

**Immigrant Women Living with HIV:
Communication with Healthcare Providers and the
Role of Interpreters on Accessing Healthcare
Services in Norway**

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Abstract

Objective:

This study aims to explore immigrant women living with HIV's perception of their communication with healthcare providers, the use of interpreters and access to health information.

Method:

A qualitative study, gathering data through in-depth interviews and focus group discussion was used. The participants were immigrant women living with HIV in Norway and interpreters.

Result:

Communication between immigrant women living with HIV and healthcare providers is poor as a result of the language barrier present, limited consultation time with doctors, and fear of stigma. Communication is also negatively affected by the limited use of qualified interpreters and fear of using interpreters from the same country as the immigrant women. The result also shows that immigrant women living with HIV expect more health information from doctors, and want doctors to be the primary source of information about HIV.

Conclusion:

Healthcare providers need to offer health information based on individual needs and need to address the concerns of immigrant women living with HIV. In this regard information from treating doctors is most crucial. Immigrant women with HIV consider the usefulness of interpreters as very limited, mostly due to the fact that the interpreters provided by the health services compromise the patients need for confidentiality. This creates anxiety among immigrant HIV positive women, due to fear of exposing their HIV status to friends and other members their immigrant communities. The use of trained interpreters will to some extent improve communication between patients and healthcare providers, and will also reduce the breaches of patient confidentiality causing fear amongst HIV immigrant women.

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Abbreviations

HIV: Human Immune Deficiency Virus

AIDS: Acquired Immune Deficiency syndrome

FGD: Focus Group Discussion

UNAIDS: United Nations AIDS Program

WHO: World Health Organization

IMDi: The Directorate of Integration and Diversity

Fafo: An independent and multidisciplinary research foundation

GP: General Practitioner

NIPH: The Norwegian Institute of Public Health

CMC: Computer-Mediated Communication

UUS: Ullevål University Hospital

NSD: Norwegian Social Science Data Services

MSM: Men who have sex with men

MSIS: Norwegian Surveillance System for Communicable Diseases

PLWHA: People Living With HIV/AIDS

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1. Introduction

During the past 15 years or so the number of people migrating to Norway has increased significantly. The number of migrants with HIV is also increasing as more persons seek asylum or come to Norway through family reunification. The rate of newly diagnosed HIV positive people in Norway has doubled from a rate 150 cases annually in the 1990s to 299 new cases in 2008. Seventy out of 132 immigrants diagnosed in 2008 after coming to Norway are women with African origin. More than half of these immigrant women were unaware of their HIV status before they were diagnosed here in Norway (Nilsen, Blystad, & Aavitsland 2009).

Most of them are shocked by the news, and this presents a double challenge together with unknown and insecure immigration status. The majority of asylum seekers have to wait several months or even years before they find out whether they will be allowed to remain in Norway permanently. Many are afraid they will be sent out of Norway. This waiting period poses fear, insecurity and anxiety. HIV positive asylum seekers have the added burden of fear and worry regarding their health situation. The Norwegian healthcare services aspire to give quality treatment and information to HIV positive people regardless of country of origin or residential status. However, there is a growing concern that immigrant women with HIV are being marginalized. This marginalization is partly attributed to lack of knowledge among the immigrant population and partly due to language barriers (Grønningsæter, et al., 2009).

HIV positive immigrants have the need to receive understandable directions regarding available health services, health information about treatment, and information regarding medication side-effects. Much of this primary health information is delivered at refugee camps or in health centers in Norwegian. Many immigrants speak limited Norwegian or English and therefore struggle to comprehend the information they receive, thus becoming dependent on translation services. The health system is being criticized for their limited use of qualified interpreters in their encounters with immigrant patients (Emine Kale, 2006). This poses a challenge on the communication between healthcare providers and immigrants, especially for those who are new to the country and those with poor educational background.

Many immigrants suffer from various health problems such as diabetes, obesity, heart attacks, tuberculosis and HIV. It is important to understand that many African societies see HIV/AIDS as a punishment to those who failed to abide the moral laws given by God/Allah

towards human sexuality through *immoral* sexual behavior (Kebede, 2004). Women are in particular expected to behave, and thus having HIV creates extra stigma and pressure on women. African immigrant women with HIV carry a burden of guilt and shame, and prefer to hide their HIV status as much as possible, particularly due to the fear of being outcast from their society. Hiding ones HIV status is felt to be necessary to protect oneself from negative reactions (Anderson & Doyal 2004).

A communication gap is often created as a result of reluctant attitude to discuss the disease on the part of the immigrant. HIV positive immigrants are reluctant to talk about HIV because of stigma and this can hinder good communication (Moneyham, et al., 1996). HIV/AIDS can be a terrifying subject to discuss, and many immigrants choose to avert it. For others it reminds them of an issue of life which they want to forget and they choose not to discuss it. This situation, therefore, has inspired me to explore and document HIV infected immigrant women's perception of good communication, including their access to relevant health information and the use of interpreters in facilitating communication with healthcare providers in Norway. Moreover, I would like to inspire interested researchers to use the results of this study as a baseline in their work to bring better understanding in this area.

1.1 Objectives of the study

Main objective:

- To explore the communication between immigrant women living with HIV and healthcare providers in Norway.

Specific objectives:

- To investigate immigrant women living with HIV's perception and need for good communication with healthcare providers.
- To explore the use of interpreters in facilitating the communication between healthcare providers and immigrant women living with HIV.
- To explore the experience of immigrant women living with HIV on accessing health information.

1.1.1 Justification

No study has been done in Norway on communication between immigrant women living with HIV and healthcare providers.

1.1.2 Research question

How do immigrant women living with HIV perceive their communication with healthcare providers?

Does the use of interpreters facilitate or hinder good communication between immigrant women living with HIV and healthcare providers?

Do immigrant women living with HIV get enough health information?

1.2 Structure of the thesis

In the second chapter I will present some background information about HIV/AIDS globally and also in Norway, with a particular focus on women from Sub-Saharan Africa. This chapter will also review relevant and available literature on gaining access to health information, doctor to patient communication and the role of interpreters in healthcare communication. The chapter will be concluded by looking into literature on barriers affecting experiences of immigrant women living with HIV. Much of the literature in the area looks into the impact of stigma on the lives of immigrant women living with HIV. The third chapter discusses the qualitative methods used during the data collection. This chapter addresses the experiences and observations of this researcher during in the process of collecting data for this study. The fourth chapter presents the main findings of the study. The findings reflect the perception of the informants and will be presented with the aim of addressing the specific objectives of the study. The fifth and final chapter discusses the findings based on the literature review. The thesis will be summarized with concluding remarks, followed by recommendations by informants and also this researcher.

2. Background

2.1 HIV/AIDS – a global pandemic

Acquired Immunodeficiency Syndrome (AIDS) is a disease caused by Human Immune Deficiency Virus (HIV), and it destroys the body's natural protection from infection, and in some cases resulting in death. The most significant factors cited for the HIV epidemics are unprotected sex, sex between men (MSM), and the use of contaminated drug-injecting equipment by two or more people on the same occasion (*Global report: UNAIDS report on the global aids epidemic 2010*, 2010)

According to UNAIDS recent report a total number of 33.3 million people are infected with HIV worldwide at the end of 2009. Sub Saharan Africa is hit hardest by the epidemics with 22.5 million people living with the virus. During the first phase of the epidemic, the infection was more prevalent among gay people. After few years, however, the virus has widely spread among heterosexual people. According to the UNAIDS report the most disadvantaged among the later ones are women from sub-Saharan African countries, and 80% of all women with HIV live in the region.

More women than men in Sub-Saharan Africa live with HIV, and young women aged 15–24 years are as eight times more likely than men to be HIV positive (*Global report: UNAIDS report on the global aids epidemic 2010*, 2010). HIV prevention work on women in the region has been mired by poverty, gender inequality, and inequity in health and the education system (Parker, Easton, & Klein, 2000). Women have greater biological vulnerability to HIV infection, and suffer from low socioeconomic and political status, unequal access to education, and fear of violence (UNAIDS Report 2010). Gender inequality means also that women in sub-Saharan Africa have little capacity to negotiate safer sex, access the services they need, and utilize opportunities for empowerment (Parker, et al., 2000). HIV infected people are also exposed to social stigma and psychological pressure in their daily lives (Kleven, 2006).

In the 1980's HIV/AIDS was a life threatening terminal illness. But now it is considered as a manageable chronic disease (Bruun, et al., 2006). Although HIV is not a curable disease, requiring continued adherence to antiretroviral treatment, counseling, psychosocial support, access to good nutrition, safe water and basic hygiene, the possibility of HIV developing into

AIDS is reduced significantly. HIV treatments in Sub-Saharan African countries has improved significantly in the last few years, and nearly 37% of people eligible for treatment were able to access life-saving medicines in 2009. According to UNAIDS Global Report (2010), an estimated 5.2 million people in low and middle income countries were receiving antiretroviral therapy. However, the vast majority of Africans living with HIV, of which women are strongly represented, continue to suffer from lack of affordable medication. Most women in African Countries lack the resources that might be needed to cover the costs of HIV treatment (Parker, et al., 2000). To avoid HIV related problems in their native countries and seek for a better life, better treatment and better social acceptance in the western world, many Africans living with HIV are forced to migrate to developed countries (Karago-Odongo 2008).

2.1.1 HIV in Norway

According to the Norwegian Institute of Public Health (NIPH), between 1984 and 2008, 4086 people have been infected by HIV in Norway of whom 2748 are men and 1338 are women. This is primarily as a result of an increase on HIV cases among men who have sex with men, and an increase on the number of HIV infected immigrants coming to Norway. The former is a group with the highest risk of being infected by HIV and has a 70% prevalence rate compared to heterosexual men in Norway (Nilsen, Blystad, & Aavitsland 2009).

Refugees, asylum seekers and family reunited immigrants make up the second high HIV prevalence group in Norway. It has been estimated that about 100 HIV infected immigrants come to Norway every year (Aavitsland & Nilsen, 2006). According to a report by Norwegian Institute of Public Health (2010), a significant number of HIV-positive immigrants come from conflict areas highly affected by HIV epidemics and in particular from Eastern Africa.

As it is the case for other Western countries, African immigrant women living with HIV come to Norway to improve their livelihood, get protection from prosecution, avoid and most importantly secure better treatment and medication. However, despite easy access to treatment in Norway, immigrant women with HIV are reportedly marginalized (Grønningsæter et. al, 2009). Some of the factors contributing to this include language barrier, stigma, and lack of adequate information about the disease and its treatment (Kleven, 2006). According to the National HIV strategy document (2009-2014), the Norwegian authorities are urged to give more attention to the challenges immigrant women meet, since they are susceptible to HIV infection and marginalization (National HIV strategy 2009). Language difficulties and low

level of health literacy limit immigrant women from actively seeking information and they create barriers in communicating with healthcare providers.

2.2 Literature on Healthcare information and communication

A good quality health service implies good communication between patient and healthcare providers as well as access to adequate health information. This is necessary in order for the patient to feel well cared for and respected, and also to secure good treatment and adherence. To this end, there are many difficult discussions that HIV treatment providers must initiate; this includes delivering HIV positive results, clarifying treatment options, exploring values and goals of care, and discussing prognosis and advance care planning (Matiassek & Wynia 2006). Most HIV positive people, especially those who are recently diagnosed, may not have enough knowledge or may have wrong perceptions about the disease. When patients receive the news about their HIV positive status the first time, they react with shock, fear, and guilt (Kleven, 2006). They fear that it might be the end of their life. Thus, healthcare providers can play a significant role in acknowledging the feelings of the patients, clarifying the myths and misunderstandings about the disease, as well as doing individual follow up of the patients. A good communication will in this regard improve patient's knowledge and information need, and reduce individuals' fear of and direct association of the infection with death.

The Norwegian Patients' Rights Law states that all patients have the right to necessary information about their health condition and the content of the health service they get. And the information shall be suited to the receiving individual's situation such as age, maturity, experience, cultural and language background (*Jf Patient rights law §3-2 and 3-5*). The healthcare providers have the responsibility to provide necessary information, and as much as possible insure that a patient understands the content and meaning of the information (E. Kale & Syed, 2010). The immigrant patient is often dependent on healthcare providers' ability and willingness to explain health information in a language the former comprehends. Newly arrived and even settled refugees and asylum seekers will normally have difficulties of communicating in Norwegian or in some cases in English, which is widely spoken among health professionals.

According to a survey by The Directorate of Integration and Diversity (IMDi), the major barrier of communication between doctors and their immigrant patients relates to the latter's inability to communicate in Norwegian (Kavli & Andersen, 2007). General Practitioners in the survey responded that lack of Norwegian fluency among patients contributes to negative

consequences for patients in the form of limited possibilities to discover symptoms, and higher risk of wrong diagnosis and wrong treatment. The result of the survey shows that the use of qualified interpreters will reduce the above mentioned risks significantly. By qualification, they mean interpreters' general language fluency, knowledge of medical terminologies and interpreting techniques and rules (Kavli & Andersen, 2007).

Also The Norwegian National HIV strategy document (2009-2014) emphasizes the necessity of using interpreters when healthcare providers communicate with immigrants living with HIV. The specialist health services at hospitals and polyclinics, which are responsible for the treatment of HIV positive people, are obliged to provide interpreters when patients with HIV meet healthcare providers.

2.2.1 Accessing healthcare information for immigrants with HIV/AIDS

Immigrants have many health problems that are preventable. Yet, language problem, lack of access to information and that of qualified interpreters create various health challenges for them (Aambø, 2004). In other words, miscommunication, misinterpretation and cultural differences contribute to poor health outcome among immigrants.

Andrulis and Brach (2007) addressed the interrelationship between health literacy, culture, and language and the importance of their intersection to improve healthcare for culturally diverse and limited English proficiency patients in the US. By health literacy, they mean "*the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*". Limited health literacy is associated with low health knowledge, misinterpretation of prescriptions, and lower receipt of preventive services. The study identifies culturally diverse individuals with limited literacy and limited English proficiency as among the most vulnerable patients (Andrulis & Brach, 2007).

Effective patient-provider interactions are fundamental to achieve successful clinical outcomes. Healthcare providers need to have an understanding about immigrant patients' health literacy, culture, and language, and use that information to improve communication and self-management support. It is also essential that written materials have to be easy to read and culturally and linguistically appropriate. Electronic mediums and audiovisual materials such as DVD and CD-ROMs should rather be a compliment than substitutes to discussions with clinicians (Andrulis & Brach, 2007). An exploratory study was conducted in Canada to

determine ways in which people living with HIV/AIDS collaborate to meet treatment information needs and what role Internet-based computer-mediated communication (CMC) played in meeting this goal. A variety of both off- and online web-based and print resources were used to learn about HIV/AIDS treatment information. All participants were communicating with others, primarily in person, and most desired anecdotal treatment information. However, few reported using CMC to accomplish this goal (O'Grady, 2008).

A study in the USA on health information sources among multiethnic minorities showed that the most common source of health information is a health professional (40%), followed by television(21%), hospitals or doctors' offices(18%), books(17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). The study also shows that females are more likely than males to get their health information from a doctor/health professional. The results also showed that educated people rely more on Television as a source of information compared to less educated ones while recent immigrants and less educated people were more likely to report that they were unable to get health information (O'Malley, Kerner, & Johnson, 1999). Some of the difficulties of getting health information arise from low literacy levels, poorer access to media and health professionals, preoccupation among recent immigrants with socioeconomic survival, or lack of knowledge of where to go health information. The study highlights the importance of doctor-patient communication combined with grassroots community-based efforts in information dissemination to higher risk group such as immigrants (O'Malley, et al., 1999).

The above discussions clearly show that the most preferred source of information for immigrants with low health literacy is direct communication with healthcare professionals, most importantly doctors. The discussion shows also that information sources such as Television and the Internet, books, magazines still remain important but only as a supplement to a culturally and linguistically conscious doctor-patient communication, a topic to be discussed next.

2.2.2 Healthcare provider-patient communication

A successful doctor-patient communication is a result of effective communication in which the patient describes his symptoms while the doctor listens. And then the doctor explains effectively a diagnosis, treatment or prevention plan, which the patient must understand and endorse (Lukoschek, Fazzari, & Marantz, 2003). Various studies confirm that patients without common language with healthcare providers are the most disadvantaged ones. Owing to that

limitation, among others, immigrant populations are the most vulnerable healthcare consumers, and suffer from higher rates of morbidity and mortality than other segments of the population. They often have to struggle with their poor levels of language and health literacy. These problems are strengthened by cultural differences and economic problems (Matiasek & Wynia, 2008).

Clear communication is needed between doctors and patients. Failure to communicate clearly can result in unnecessary return for treatment or/and it can lead to more ailment or adverse events (Simpson et al., 1991). A clear communication includes limiting the number of messages delivered at one time, using simplified, jargon-free language, and having patients explain what they have been told and repeating the information until it is clear the patient understands. Therefore, good communication and relationship between HIV positive immigrants and doctors can play a significant role in influencing the treatment decision, and is closely linked with improved patient satisfaction, adherence to medical recommendations, and health outcomes (Thomas, Aggleton, & Anderson, 2010).

Research on doctor-patient communication makes distinctions between disease-centered approach and the patient-centered approach. In the disease-centered approach, the doctor concentrates on his or her own agenda notes and where he or she seeks to reach a clear diagnosis of the problem through ‘text-book’ style enquiries about the patient’s symptoms and medical history (Williams, et al., 1998). The doctor suggests certain best health-related values that can be realized in the clinical situation. This approach is also known as ‘The paternalistic model’, in which the doctor presents the patient with selected information that will encourage the patient to choose the intervention the doctor considers best. (Graugaard, 2003). This notion of the doctor “knows best” has dominated research on doctor-patient communication. Immigrants patients from Sub-Saharan African countries are heavily influenced by this approach, and the legitimacy of biomedical knowledge and doctors’ influence and dominance over their views (Thomas, et al., 2010).

Recent studies have shifted their focus towards egalitarian relationship between doctors and patients in which the patient’s resourcefulness and expertise is given wider legitimacy (Williams, et al., 1998). This approach assumes that the conventional biomedical model is incomplete and suggests doctors must be able to empower patients. It renounces the traditional power balance in which the doctor has the upper hand in the doctor-patient relationship (Graugaard, 2003). In this approach the patient-centered approach, the

doctor works with the patient's agenda listening and responding to what the patient says and the doctor-patient relationship is considered egalitarian. The doctor enables the patient to express his or her reasons for attending, including their symptoms, ideas, in feelings and expectations.

This approach is however seen as impractical with regard to HIV positive immigrants from Sub-Saharan Africa (Thomas, et al., 2010). There is deep-rooted professional power among doctors and the structural constraints which govern resource accessibility. According to Thomas, et al (2010) African Immigrants living with HIV have high level of respect for their doctors and they may not feel secure enough to change the power balance. African immigrants living with HIV consider the fact that doctors had been the major factor in their survival, and therefore place ultimate faith in doctors (Thomas, et al., 2010). As a result they give the entire responsibility to doctors, and have minimum involvement in decision making with regard to their treatment.

Information from healthcare providers and patient satisfaction

Giving information to patients is complex, yet doctors must be able to provide health information and ensure the information is understood by patients. Studies confirm that patients' comprehension of health information was associated with patient satisfaction. Satisfaction is by far the most used outcome measure within communication research (Lukoschek, et al., 2003). Studies show that a positive relation between the amount of information that the doctor provides for the patient and patient satisfaction. Information provision by doctors specifically during the examination, but also during the concluding section of the consultations has been found to be related to increased patient satisfaction (Williams, et al., 1998). Similarly, the personal manner of the doctor during consulting has raised patient satisfaction. Positive verbal behavior and partnership building during consultations has also been reported to be directly related to the level of patient satisfaction.

Doctor-patient relationship and the expression of affection during consultations are found to be important factors in enhancing patient satisfaction. Doctor anger or disagreements or negative tone expressed by either the doctor or the patient is negatively related to patient satisfaction (Williams, et al., 1998). Thus a good communication between doctors and immigrants living with HIV is crucial to improve health outcomes. Good doctor-patient communication exerts a positive influence not only on the emotional health of the

patient, but also on symptom resolution, functional and physiologic status and pain control (Williams, et al., 1998).

2.2.3 The role of interpreters in health communication

Language barriers are a growing problem for people seeking medical care. Many patients with limited language either struggle to communicate with their clinicians or turn to family members, friends, or others. These barriers can lead to serious difficulties during medical encounters, such as lack of understanding to discharge instructions, lack of adherence to recommended treatment, and lack of patients' enthusiasm to return for follow-up visits. Besides, healthcare providers might order diagnostic tests and compromise patient's access to health information (Bagchi et al., 2011). Problems associated with language barriers can be solved if a qualified interpreter is provided during communication between the two parties, namely the doctor and the patient (E. Kale & Syed, 2010).

An interpreter is defined as a neutral and qualified person who facilitates an oral connection in a conversation between two persons who do not speak the same language. An interpreter is also a person who gets paid to translate and with no or limited personal relationship with a patient (Svela, 2007). An interpreter makes oral translations of conversations between the patient and the healthcare worker (Svela, 2007). The interpreter does not need to be in the same place where the conversation occurs, but the translation happens at the same time as the conversation takes place. An interpreter plays an important role in an intercultural meeting between a healthcare provider and immigrant patient. She translates expressions of the patient and the healthcare provider, and meanings from one cultural context to equivalent meaning in another cultural context. It is important that the interpreter masters cultural codes of both patient and healthcare provider (Jareg & Pettersen, 2006). In health services, there is a strong correlation between availability of interpreters and patient satisfaction. Patients who need medical interpreting services but who only sometimes or never receive them reported lowest rating. On the other hand patients who need interpreters and were provided regularly reported the highest ratings (Morales, Elliott, Weech-Maldonado, & Hays, 2006).

Even more, using qualified interpreters improve the communication between patients and healthcare providers (Bagchi, et al., 2011). Professionally trained interpreters are believed to follow and respect Ethical codes of conduct for interpreters, thus securing unbiased, timely and accurate translation of information between the patient and the healthcare worker (Svela, 2007). Some of the guidelines in the Ethics code of conduct for interpreters include:

- Not to engage in providing translation services without the necessary qualification;
- Not to be related to or be part in the translation;
- Taking no sides or never allowing their own personal attitude or opinion;
- Translating everything that is said, without adding or changing what is being said;
- Respecting confidentiality;
- Not misusing/abusing the information acquired during the translation for their own self-interest; and
- Informing situations suggesting that the translation is being conducted in an irresponsible way.

These guidelines are expected to be respected by interpreters in Norway. There is an increasing awareness about these guidelines among interpreters and users of interpreters in the health services. However, studies show that there is underutilization of professionally trained interpreters, and rather a large proportion of untrained interpreters with limited respect for these guidelines work in the healthcare services in Norway (E. Kale & Syed, 2010)

Healthcare providers' perspective

There are several studies carried out in Norway which discuss the use of interpreters in the public sector in general, and few have addressed the topic with regard to health services in particular. The studies largely discuss the view of healthcare providers or have based their source of information on accounts obtained from healthcare providers. Some of these studies will be reviewed in this chapter.

A study by Kale and Syed (2010) looked into health providers' communication with immigrant patients and the use of interpreters in Oslo in the sector. It was a cross-sectional study with a sample size of 453 healthcare providers on the use of interpreters to effect communication with patients who have language difficulties. The healthcare providers considered for this study mainly worked with immigrant patients. Out of 453 healthcare providers 26% were physicians & 51% nurses, and the study focused on the two occupational groups. The result of the study reveals that only (30 %?) thirty percent of the healthcare providers use interpreters during communication with immigrant patients. Yet, more than fifty percent of the healthcare providers in the study are aware of the importance of using interpreters.

The healthcare providers admitted that they usually resort to easily available solutions such as unprofessional interpreters, and family or friends brought by patients themselves. In some

cases, underage children are used as translators, especially when the patient needs to be helped immediately. In some other cases, healthcare providers avoided using interpreters even though there was a clear indication that patients needed to communicate through an interpreter. And this often happened with doctors and nurses in 28.8% and 41.5 % of the cases respectively. These healthcare providers, however, recognize the need to integrate the use of interpreters as part of health services although, in practice, they did not prioritize the use of qualified interpreters. The use of qualified interpreters mainly depends on individual healthcare worker. And there is a need to raise awareness among health providers on their legal obligations to secure sufficient communication with patients experiencing language barriers (E. Kale & Syed, 2010).

Generally, there is a huge concern on the use of interpreters in the health services in Norway. Some of the problems mentioned are: lack of routine to control the qualification of interpreters, big uncertainty on when to use interpreters, uncertainty on who is responsible to assign and make quality control of interpreters, and which agency is to cover the cost for interpreting services. Pursuant to the Patients' Rights Law, healthcare institutions have the responsibility to guarantee patients the right to information. Thus, the responsibility lies on healthcare providers to secure qualified interpreters (E. Kale & Syed, 2010)

Svela (2007) in her master's thesis, *The Difficult role of the Interpreter*, discusses the dilemma of being a trained interpreter in the health services in Norway. She argues that the interpreter is sometimes stuck between different expectations from patients and Norwegian speaking healthcare providers. Both patients and healthcare providers have their own expectations which may not necessarily be within the limits and bounds of the ethical guidelines for the interpreter, a situation that makes the interpreter's role too demanding.

Svela (2007) argues that the healthcare providers expect the interpreter to translate accurately at the same time sum up the conversation. In some cases the healthcare providers expect the interpreter to be their cultural informant. The interpreter is also expected to make the patient understand the healthcare providers' cultural frame of reference, not the other way round. There is a lack of awareness among healthcare providers on the rules that guide the use of interpreters (Svela, 2007).

Interpreters' perspective

Due mainly to lack of research on health communication in the health services in Norway from the interpreter's perspectives, relevant reference is made to few studies from other countries. In her summary of some of the literature available in the area, Svela (2007) has revealed that besides direct verbal translation, interpreters consider themselves to be responsible for the communication across language and culture, and also interfere with or stop possible miscommunications between the health provider and the patient. In the process, almost half of the interpreters tend to take part in favor of one of the interacting parties (Svela, 2007) .

Fatahi et.al (2005) studied interpreters' experiences of general practitioner-patient encounters in Sweden. The interpreters in the study assumed their main responsibility to be passing information as correctly as possible between the patient and the GP, and pointed out that they experience different challenges in their daily work. Some of the challenges mentioned are balancing the GP-patient-interpreter relationship, the role of the interpreter in relation to other healthcare providers, cultural inequalities, time constraints of the translation procedure, and diverse health beliefs. The study further reported that while maintaining a unique and separate relationship with the patient, interpreters, nevertheless, saw themselves often as part of the health service staff. Even though these are qualified interpreters, they still found it difficult to balance their profession and their culture (Fatahi, Mattsson, Hasanpoor and Skott 2005).

In Svela's (2007) study, cultural communication barriers are seen as common challenges during translation. 42% of the interpreters responded that there are different understandings of health between immigrant patients and healthcare providers. The same study also shows that 40% of the interpreters believe that communication between healthcare providers and patients with other ethnic background could improve, if healthcare providers had more information about health systems in other countries. Although the interpreters would like to reduce the cultural gap that hinders communication between healthcare providers and immigrant patients, the interpreters feel that their cultural competence is not utilized enough. They consider cultural competence as equally important as language fluency and translation ability in order to be a good interpreter. The interpreters feel responsibility for the communication between healthcare providers and patients (Svela, 2007). These statements, however, contradict with some of the ethical guidelines which dictate the interpreter to translate without taking any other role than translating everything that is being said.

Patients' perspectives

As in the case of interpreters, systematic research is scant on the view of HIV positive immigrants in Norway on the use of interpreters. There are, however, studies that have touched upon the use of interpreters in particular relation to HIV positive immigrants' fear of stigma. Svela (2007) reviews some studies in which the patient sees the interpreter as an actor to modify and give explanations in health consultations. These studies emphasize the importance of meeting the immigrant patients in a culturally sensitive way. And trust in the interpreter is given a significant place, and it can be built through time and the patient needs time to come into contact with the same interpreter repeatedly before he/she is able to communicate freely (Svela, 2007).

Djuve & Pettersen (1998) studied ethnic minorities' understanding of the healthcare services in Norway. The result showed that 32, 2% believed that hospital personnel did not understand what the patients said or did not help as desired by the patients. Only 13, 2% said that they were offered interpreters during medical encounter. 48, 1% responded, on the other hand, that they had someone with them to assist in translation. The result shows that there is a significant need for assigning interpreters for patients. The result also indicated that ethnic minorities prefer to use a close relative or friend who they can trust to an outsider (interpreters) so as to feel more confident that confidential information will not leak out. They also prefer to use close relatives because they feel that they have shared views and meanings with them. A minority patient may however use an interpreter if he/she trusts that the interpreter respects specially confidentiality but also the overall ethical guidelines. It is also equally important that the interpreter is considered as someone who masters both languages fluently.

Svela (2007) referred to another study from Great Britain in which ethnic minority patients appreciate the interpreter's ability in interpersonal qualities such as personality and attitude as much as they value their ability to interpret. As a result, patients seem to prefer interpreters who "empathies with them, understanding and relating to their situation". They also wanted interpreters who are on their side and give them a helping hand in their communication with healthcare providers (Svela, 2007). Thus, the interpreters are expected to be on the patients' side. This crosses with the neutrality element of the ethical guideline. In some cases, professional interpreters are not needed because of their rigid compliance with the ethical guidelines. It is often for this reason that family members or relatives are preferred as

they do not necessarily abide by the ethical guidelines (Djuve & Pettersen, 1998). Instead, they are free to define their role as an interpreter/helper. Family members are also preferred because they use simplified language and description understandable to the patient. The family members inform the patient by using supplementary expressions and explanations, a duty that a professional interpreter may leave to the healthcare worker. It is especially elderly patients with limited knowledge about medical terminologies who seem to prefer such types of translations.

In another study that involved a focus group discussion including 5 healthcare providers, 5 minority women and 5 patients from a rehabilitation center in Oslo showed that lack of trust in the interpreter's ability to keep confidentiality has been perceived to be the main problem. With some ethnic minority groups comprising a small number as a community, it is quite possible that the interpreter and the patient meet in other social gatherings where the former may compromise confidentiality (Aambø 2004). Also some patients fear that the interpreter might pass over confidential information to authorities in their home countries. This last part shows that patients evaluate the interpreter based on his/her personal abilities and qualities. And that makes it very important for patients to use interpreters who they can trust, and who they believe respect the ethical guidelines in general and confidentiality in particular (Emine Kale, 2006). Patients clearly express the need to use few or one trusted interpreter rather than several others in which the patient is forced to hide useful information from the healthcare worker due to lack of trust (Djuve & Pettersen, 1998).

2.3 Barriers on African immigrant women living with HIV

As mentioned earlier, African immigrant women represent a significant number of HIV cases in Norway and other western countries. They experience unique and deeply rooted socio-cultural and structural barriers interconnected with gender, race, political and economic conditions (Karago-Odongo, 2008). For many, being an immigrant by itself creates a heavy burden associated with coping within a new society culturally, economically and socially. African immigrants often face skeptical host society unwilling to include them in the main stream of everyday life. Having HIV thus brings double burden and creates a range of emotions for those African immigrants who are diagnosed for the first time. Some of the reactions include shock, disbelief, and confusion and fear of premature death. Many African immigrants lack knowledge about HIV/AIDS and available treatments, which will in turn contribute to stress. The stress creates a psychological pressure and many become uncertain as

regards the development of the disease and its side effects (Kleven, 2006). For some, it becomes difficult to manage unpredictability of HIV. Some manage to cope by understanding their body signs while others fight the stress through self-control over their body, and by acquiring knowledge about symptoms and side effects (Kleven, 2006). Others choose to hide their symptoms as a strategy to protect them from the worsening progress of the disease.

A study among health service providers to immigrants living with HIV/AIDS in Toronto, Canada, identified such challenges for immigrant women living with HIV as language barriers, stigma, discrimination, poverty, immigration status, racism, and marginalization (Karago-Odongo, 2008). Stigma and language barriers are identified as major obstacles experienced by immigrants living with HIV. The study further showed that house wives among immigrant women, who are unskilled and unemployed, lack economic opportunities and autonomy, a situation adding up to their increasing dependency on their spouses. Women in such situations are often deprived of rights and may face lack of sexual control over their body. The study also shows that the healthcare environment in Canada imposes substantial barriers and hinders access to health services. African immigrant women with HIV tend to utilize healthcare services less and receive critical diagnosis and treatment significantly later than other populations largely due to cultural, linguistic, racial, gender, and class barriers embedded within the healthcare system (Karago-Odongo, 2008). African immigrants living with HIV show reluctance to access healthcare services including HIV/AIDS education, treatment, support and care due to racist tendencies within the healthcare system (Ndirangu & Evans, 2009). In some cases African immigrants choose to wait their HIV diagnosis due to fear of losing their job, deportation, and that of stigma (Karago-Odongo, 2008b).

2.3.1 Immigration status

According to UNAIDS (2010), some fifty-one countries, territories, and entities impose some form of restriction on the entry, stay, and residence of people living with HIV (*Global report: UNAIDS report on the global aids epidemic 2010*, 2010). In Canada, HIV positive immigrants without refugee status can be denied residence permit on the ground of excessive demand on health or social services (Tharao and Massaquoi 2006). Thus, many asylum seekers choose to hide their HIV status until they receive their residence permit which also means that they avoid getting treatment by risking their lives.

Numerous barriers related to settlement exist for immigrants in many Western countries irrespective of their HIV status. Just upon arrival, immigrants and refugees face legal and policy barriers including restricted access to the determination process and social services. It is therefore overwhelming for newcomers who are HIV positive juggling the many issues that they have to deal with because of their immigration status (Karago-Odongo, 2008). Immigrants normally intend to start work and settle immediately after they first arrive in the Western countries. However, when they receive an HIV positive diagnosis, their lives are negatively impacted. Refugee claimants wait often for a long period under the pending status until the immigration authorities decide whether or not they can stay in the host countries (Ndirangu & Evans, 2009). This can significantly increase their stress and anxiety. Despite their low economic abilities, newcomers do not inform families left behind at their home countries of their HIV status. This is mainly because they find it rather anxious to confide with their families regarding their 'sad' state of being as these families instead expect them to address their economic strains back home. In response to that expectation, the immigrants send home the money they receive as remittances. This in turn causes financial constraints that some patients choose not to take their medication or not to adhere to nutrition guidelines as advised (Karago-Odongo, 2008).

HIV positive immigrants from sub-Saharan African countries meet double challenges when they arrive in Norway. They are not allowed to apply for work permit unless they are citizens of a European country. Thus, they are forced to seek asylum to get residence permit. Then, as asylum seekers they need to live in Refugee camps where they will undergo obligatory Health Checks. According to Norwegian Directorate of Health, asylum seekers are advised by the healthcare providers at the temporary refugee camps to take the HIV-test. Many asylum seekers find out their HIV status after these tests. Some of them seek Asylum in order to get medication and treatment, which is secured by Norwegian law. Those who have experienced difficulties in getting HIV medications in their home countries welcome this provision as a very important advantage of immigrating to Norway. However, this situation may be short lived if and when their application for a residence permit is rejected and if they have to leave the country. Many HIV positive asylum seekers go through an insecure time waiting for their residence permit, engulfed by fear of being thrown out of the country and consequently of losing long term and lifesaving HIV medication (Ndirangu & Evans, 2009).

2.3.2 Stigma and lack of disclosure of HIV status

Stigma is one of the most significant barriers that affect Immigrant women living with HIV from accessing health services (Karago-Odongo, 2008). The notion of stigma is linked to feelings of shame and disgrace (Goffman, 1963). It comes from the belief that being HIV positive is tantamount to premature death. HIV-related stigma often has a negative impact on health; it affects social support networks, employment and working conditions, personal health practices, and coping skills. A person may keep his/her HIV status secret to avoid discrimination in the workplace. Stigma also affects attitudes about sexuality and culture (i.e. sexual practices, notions of morality and promiscuity, orientation, poverty) (Kebede, 2004). Immigrants living with HIV in Norway experience stigma with in their own immigrant communities, and self-stigmatization is also quite common. It can result in low self-esteem and poor management of one's life (Grønningsæter, et al., 2009). According to UNAIDS report (2010) *"In Rwanda, more than 50% were verbally insulted, 36% physically harassed and 20% physically assaulted, 65% experienced loss of job or income and 88% were denied access to family planning services due to their HIV status. In the United Kingdom, 17% reported having been denied health care"* (UNAIDS Global Report 2010 p.124).

In the same report, significantly a high percentage of respondents in all countries *"reported internalized stigma: feeling ashamed, guilty, suicidal, and blameworthy"*. Further, people living with HIV continue *"to experience high levels of HIV-related stigma and discrimination. Slightly less than half of respondents experienced negative attitudes or exclusion from family members. Other experiences in at least one third of the sample included loss of employment, refusal of care by health care workers, social or vocational exclusion, and/or involuntary disclosure"* (UNAIDS 2010 p.124). Working to reduce stigma and discrimination against people living with HIV and members of other marginalized groups help to provide social environments that are effective against the spread of HIV and promote more general mental and physical well-being (*Global report: UNAIDS report on the global aids epidemic 2010*, 2010).

Studies show that HIV infected people choose not to disclose their HIV status due to fear of stigma (Kleven, 2006). Lack of openness limits the possibility of getting appropriate treatment, and also care from family members and friends. This is widely visible among Immigrants living with HIV (Anderson & Doyle 2004). They become insecure about the reactions of their close family members and friends. The stigma and fear is mainly caused by lack of adequate information about HIV and AIDS among those who are infected with HIV,

and their family and friends. Many immigrant women living with HIV suffer from burden of isolation and loneliness, in addition to the insecurity created by unpredictability of the development of the disease (Ndirangu & Evans, 2009).

Karago-Odongo (2008) discovered that African immigrants living with HIV/AIDS endeavor to maintain their anonymity by shying away from the nearest clinics in their neighborhood and walking unnoticed to the supporting agencies for People Living with HIV/AIDS (PLWHA). They also avoid using interpreters within their community while seeing healthcare professionals. All these sinister actions emanate from fear of being stigmatized by fellow immigrants. These HIV positive immigrants also worry about losing their jobs or being deported out of the country if their status were to be known. Furthermore, they fear that by disclosing their HIV status, they incur isolation, a situation that further shrinks an already limited support system. They are also afraid that their condition denies them any chance of securing professional jobs, and alienates them from their existing connections within their ethnic communities (Karago-Odongo, 2008b).

2.3.3 Discrimination and cultural barrier in medical communication

Studies on immigrant and minority health cite quite often cultural and ethnic differences as barriers to effective doctor-patient relationship. A study in the USA show that factors such as ethnicity and appearance (among others) influence physician behavior's toward the patient. Physicians were rated higher on interviewing and empathy with Anglo-American than other minority patients (Graugaard, 2003). Studies show also that HIV positive Immigrant patients get less attention and experience discrimination by healthcare providers. Discrimination by healthcare providers pushes away immigrant people living with HIV, from healthcare services, by ultimately limiting their access for treatment (Karago-Odongo, 2008).

Schouten and Meeuwesen (2005) also reviewed the role of cultural differences in medical communication. Their findings reveal that doctors behave less affectionate when they interact with ethnic minority patients compared to white patients. And they do not engage much in social talk, and are less friendly and concerned with minority patients. In the process, patients' comments and opinions were, more often than not, ignored by their doctors. The doctors often determined the direction of the conversation and patients are made to act politely and submissively. The review also found out that ethnic minority patients are less

verbally expressive, less assertive and less affective during medical encounter than their white counterparts (Schouten, Meeuwesen, & Harmsen, 2005).

Summary

In this chapter, attempt has been made to relate the broad discussion on health information and communication to the experiences of immigrants living with HIV. To that end, I have highlighted studies that address barriers such as stigma and their implications on the livelihood of immigrants living with HIV. I have looked at researches on access to health information in particular connection to the need to provide adequate information to immigrants, thereby ultimately strengthening their knowledge and coping strategy to tackle the difficulties of HIV.

In my review of the situation of doctor patient communication, I have found it interesting to know that the literature is based on the general topic of doctor-patient communication with little attention to communication between particularly immigrant women living with HIV and their doctors. A similar observation could be made about the body of research on interpreters in the healthcare sector in Norway in which the issue of using interpreters in health services in general and to some extent in the field of psychiatry has been approached mostly from the views of health service providers. A few international studies have, nevertheless, taken up the interpreters' points of view. Few other studies have also documented the perspectives of immigrant patient views. But none of these studies has tackled the situation of immigrant women living with HIV in particular and their views about the use of interpreters in healthcare services. My study, thus, attempts to narrow that gap a bit by exploring HIV immigrant women's experiences and views on communication with healthcare providers.

3 Methodology

3.1 Study design

In this study a qualitative research approach was chosen to collect data. Qualitative research methods are increasingly being used in health services research, alongside the experimental, quantitative methods used in clinical and biomedical research. The qualitative method uses narratives and observations rather than numerical data as in quantitative methods (Pope & Mays, 1995). The qualitative research allows the researcher and the research participant to work together to document and develop interpretations of events or situations relative to a specific research question (Kvale, 1996). The specific research question in this study is geared to let Immigrant women living with HIV come forward with their opinions based on their own experiences, thoughts and feelings connected to their situations as HIV-positive people in Norway. The qualitative method has allowed the women to feel at ease, because the study was conducted in familiar environment/natural surroundings in which immigrant women living with HIV chose, felt safe and comfortable to express their views. This study focused less on the number of participants, rather on reaching women's feelings, experiences, opinions and ideas that are spoken and non-spoken. The informants are immigrant women living with HIV from different African countries with different cultural, religious and educational backgrounds and with different civil status. I believe that a qualitative method is better suited to capture the subjective opinion of these women with diverse background.

Qualitative research includes data collection methods such as focus group discussions, interviews, document analysis, and participant observation (Holme & Solvang, 1996). This study is conducted by using one focus group discussion and 15 in-depth interviews. Despite recurrent attempts to arrange more settings, the focus group discussion was limited to one event owing to the participants' sense of insecurity to express themselves in the presence of others. The significant part of the data was, therefore, collected through in-depth interviews. Two interview guides were prepared beforehand, one for immigrant women living with HIV and one for interpreters. Both interview guides had open-ended questions. The informants were free to reflect and respond to the questions without strictly following the interview order. The semi-structured questions have made it easier to follow up respondents without losing the core points of the topic of the study. All the interviews were recorded with audiotape after the respondents gave their consent to it. Both the Focus Group Discussion and

in-depth interviews were conducted in Oslo. Below is a brief discussion on the data collecting methods for this study and challenges faced in the process.

3.1.1 Focus group discussion (FGD)

Focus group discussion (FGD) is a form of qualitative research in which a group of people are asked about their perception, opinions, beliefs, and attitude towards a situation. Questions are asked in an interactive group setting where participants are encouraged to talk, and discuss with other group members (Gibbs, 1997). It allows studying people in a more natural setting. Focus group discussions are used in studies designed to explore people's experiences of services such as health screening and in action research projects involving grass-roots participation (Kitzinger, 1994). It is an organized discussion with a group of individuals selected and assembled by researchers to discuss and comment, from personal experience, on the topic that is the subject of the researcher. Focus groups are widely used to find out public understandings of illness, health behaviors and health services (Kitzinger, 1995). Focus groups enable interactions which the researcher uses as a source of data.

Focus group discussion was chosen for this study because it draws upon respondents' attitudes, feelings, beliefs, experiences and reactions as a group of people with common challenges as Immigrant Women Living with HIV. It was done in collaboration with a PhD student at the department of pharmacy at the University of Oslo. The purpose of the discussion was to explore how the informants interact and reflect upon their situation as Immigrant women living with HIV. The day we had the focus group discussion, I and my colleague, the PhD student went to Aksept early to arrange the room and made sure we had every necessary thing ready. We brought some snacks and juice for informants. Six of the informants came on time while one came about 15 minutes late and another about 30 minutes late. Before the actual discussion began the participants were first given a short introduction and procedures of how the FGD was to be conducted. One of the employees at Aksept served as caretaker in the room.

Focus group discussions are believed to help participants to explore and clarify their views in ways that would be difficult if it was in individual interview situation. Participants in the Focus group discussion are encouraged to express their views partly as a result of the group dynamics and partly as a direct encouragement from the researchers. The method encourages participants to communicate in different ways such as jokes, anecdotes, teasing, and arguing. This way, they feel free to express themselves more easily (J. Kitzinger, 1995). I and the PhD

student had fairly less involvement limited to reminding the participants of the focal points in reference to the open ended questions that are prepared beforehand. The participants were encouraged to talk to one another, ask questions and comment on each other's experiences and points of view. We were interested in understanding what and why of their thought as they communicated in the group. We also examined how participants interacted taking their diverse background into consideration.

3.1.1 In-depth interviews

In in-depth interviews, the researcher engages in conversation in which one informant at a time shares his or her experience, opinions and views about his or her lived world. As Kvale put it, "The qualitative research interview attempts to understand the world from the subjects' point of view, to unfold the meaning of people's experiences, to uncover their lived world prior to scientific explanations"(Kvale, 1996). And the research situation for in-depth interviews is often close to everyday situation. The goal of the interview is to explore the informant's point of view, feelings and perspectives by asking questions, systematically documenting their responses and probing for deeper meaning and understanding of the responses (Kvale, 1996).

As mentioned earlier, the main focus of this study is to explore immigrant women living with HIV's perception of their communication with healthcare providers. By engaging in one to one conversational in-depth interviews, the interviewer gets the opportunity to approximate their inner thoughts and know their wishes as well as their reflections on the availability and quality of the information they receive as Immigrant women living with HIV. The strength of in-depth interviews lies thus on their quality enabling the researcher to gather data at an individual level, and that the information gathered reflects the informant's subjective understanding. In-depth interviews involve open-ended questions which allow respondents to give broader details on the topic of the research. The questions are designed in a semi-structured format so that the flow of the conversation dictates what questions are asked in which order. The process of in-depth interviews seeks understanding and interpretation of the responses as well as it necessitates clarity of meanings obtained. In-depth interviews are also conversational with a smooth transition from one topic to another. The responses are recorded with audiotapes and written notes. In-depth interviews demand a thorough planning and well thought strategies beforehand (Kvale, 1996). A concerted attempt has been made to make the

interviews in this study incorporate the above mentioned characteristics of in-depth interviews.

Once the immigrant women living with HIV agreed to participate in the in-depth interviews, they were given the right to choose locations where they would like the interviews to be done. All of them chose Aksept. Employees at Aksept made sure in advance that we had an appropriate room for each interview. In order to safeguard the informants' privacy, it was necessary to always lock the door during the interviews. All except one in-depth interview were done in English. One interview was done in an African language that I can speak. Those who needed interpreters did not wish to have professional interpreters due to fear of stigma, hence one of the social workers with multicultural background at Aksept interpreted for three informants. Four of the women spoke English and the other spoke my language that we did not need an interpreter.

Supplementary three in-depth interviews with three other interpreters (than the interpreter I used when I interviewed the three HIV positive women) were conducted in other places. One interview was done at my house with the permission of the participant; one was done in an African community centre where we were provided a vacant room and the third interview was done in a coffee shop. These interpreter informants have experiences of interpreting for immigrant women living with HIV's. The in-depth interviews with interpreter informants were conducted in English. Interviews lasted between 60 to 90 minutes.

3.2 Study Site

Initially both Aksept and Ullevål University Hospital (UUS) were approached to recruit immigrant women living with HIV. The reason being that UUS has direct contact with HIV positive people during their treatment and follow-ups, and Aksept is a centre where many HIV positive people visit and access various services. But UUS informed that they were not going to recruit immigrant women living with HIV for the in-depth interviews. Even though we succeeded to recruit some immigrant women for a focus group discussion, candidates did not show up on the date of appointment no matter how long we waited. We then conducted one FGD at Aksept, while waiting for candidates at UUS. This experience led to my decision to recruit informants for the in-depth interviews only at Aksept.

Established in 1987, Aksept is currently a resource centre for all HIV-positive people and those affected by it. Aksept is one of the programs of the Church City Mission Oslo (Kirkens Bymisjon) and is financially supported by the Oslo City Council. Any person, who in one way or another is affected by HIV/AIDS, is welcomed to contact the centre for support. At Aksept HIV infected, people meet others with different ethnic groups. Employees are also willing to meet outside and counsel those who are reluctant to visit the centre. It is open for the public three days a week and dinner is served only with a payment of 20 NOK both for guests and HIV positive people. Free tea and coffee is free from a vending machine at the entrance. The centre also arranges different events such as summer (garden) party and Christmas dinner and walking. A specific duration for three days a week to all users aside, employees at the centre are wary of allowing strangers in without prior knowledge of and approval by the users of the centre.

3.3 Study participants

There were two categories of study participants. The first category was participants consisting of eight Immigrant women living with HIV in in-depth interviews, aged between 19 to 37 years. All except one have children and one was pregnant with her second baby at the time of interviewing. All their children are HIV negative. They stayed in Norway between two weeks to four years. The time when they got diagnosed with HIV diagnose ranges between one to nine years. Two of my interviewees were open discussing their HIV status is while one can be described as partially happen and five of them not open.

Their level of education ranges from high school dropouts to university graduates. Half of them spoke English while the other half spoke very limited English and Norwegian. All the participants were from Africa. Three have residence permit in Norway and five are living in refugee camps awaiting their residence permit. Two participants were interviewed twice, one participant was interviewed three times and the remaining five had one interview each. Altogether, a total number of 15 in-depth interviews were conducted.

The following table illustrates HIV positive informants for the in-depth interview by assigned names with information on their time of diagnosis, their civil status, and the level of their HIV disclosure. Those who have told their HIV status to only their healthcare providers will be identified as “*not open*”, those who told to one or two friends or family as, “*partially open*” and those who have told to more than two people identified as “*open*”. Their age category will

be defined as: those who are between 30 to 40 years old “thirties”; between 20 to 30 years old “twenties”; those who are under 20 years old as “under twenty”.

Fictive name	Age	Marital status	Length of diagnose	Length of living in Norway	Level of openness	Place of diagnose with HIV
Jaquaty	thirties	Divorced	9 years	2 years	Not open	In Africa
Suz	thirties	Widow	8 years	4 years	Half open	In Africa
Princess	twenties	Married	1 year	4 years	Not open	In Norway
Vera	under twenty	Partner	2 years	2 years	Open	In Norway
Dora	thirties	Single	4 years	4 years	Not open	In Norway
Halma	twenties	Single	1 year	1 ½	Not open	In Norway
Kenzua	thirties	Single	2 years	1 ½	Open	In Africa
Vivian	Twenties	Single	4 years	2 weeks	Not open	In Africa

In the findings and the discussion sections, the eight HIV positive immigrant (African) women who participated in the focus group discussion will be identified as P1, P2, P3 P4, P5, P6, P7, and P8 , whereas, HIV positive women who participated in the in-depth interviews will be identified with their fictive names in the above table. Out of eight participants in the focus group discussion, four of them have participated in –depth interview as well immediately after the FGD.

The second category was that of participants in the in-depth interviews consisting of three male interpreters with African background. The three interpreters have been living in Norway between 13 to 20 years. One interpreter worked as interpreter for 9 years, another for 8 years and the third one for 2 years. All of them interpreted for Immigrant women living with HIV

and they are qualified and registered interpreters. Two of the interviews were done in English and one was done in Amharic. The number of interpreters was limited to 3 because interpreters are not the main target of the study. The responses from the interpreters are only intended to be supplementary to the responses of the immigrant women living with HIV who are the core subjects of the study. The following table introduces interpreter informants, by their assigned names, work experience, the length of stay in Norway and their gender.

Fictive Name	Gender	Work experience as interpreter	Length of living in Norway
Thomas	Male	9 years	14 years
Johnny	Male	2 years	20 years
Mick	Male	8 years	13 years

The three interpreters will be identified with their fictive names for the findings and the discussion.

3.4 Data collection

Data collection for the study involved two main techniques: focus group discussion and in-depth interviews. Both focus group discussion and in-depth interviews took place at Aksept.

Two interview guides were prepared beforehand, one for immigrant with HIV and one for interpreters. Both interview guides have open-ended questions. The informants were free to reflect and respond to the questions without strictly following the orders in which interview questions are presented to them. The semi-structured questions have made it easier to follow up respondents without losing the core points of the topic.

3.4.1 Inclusion criteria for HIV positive women

The inclusion criteria for this study was that the informants had to be women over 18 years of age, immigrant and recognized as HIV positive women in Norwegian healthcare system. I planned to recruit informants regardless of their immigration status, length of staying in Norway, origin of the country and their Norwegian fluency.

Interpreters were selected based on their experience of translating for a HIV positive person.

The inclusion criteria for the interpreters were that the informants are registered interpreters, have interpreted during doctor consultation for women living with HIV.

3.4.2 Sample selection

While awaiting approval from Norwegian Ethical Committee and Norwegian Social Science Data Services (NSD), Ullevål University Hospital and Aksept were informed about the study. Once the study proposal was approved, UUS and Aksept were re-contacted to recruit immigrant women living with HIV. Three employees at Aksept recruited all the participated informants. Some informants were selected while they were in Aksept to access services while others were accessed through phone calls. Many of the informants were living in the refugee camps outside Oslo. Thus their transport expenses were covered by the researcher.

For the focus group discussion at Ullevål doctors took the responsibility to recruit participants when Immigrant women living with HIV were attending their check-up appointments. We were provided with a separate room for candidates' safety where we sat and waited for potential participants. The room had a telephone we sometimes used to communicate with the nurse who was sending in participants to us.

Recruiting both for the focus group discussion and in-depth interviews took longer time than expected. Although employees at Aksept got informants for both the focus group discussion and in-depth interviews, they have used a lot of time and effort to convince informants. The situation at Ullevål University Hospital (UUS) was even more complicated. After spending all the week days from 18th of November 2009 to 11th of December 2009, from 8 am up to 3 pm, at UUS we managed to get to only three volunteers who again changed their minds. One gave us a wrong telephone number, another never answered her phone and the other one changed her mind after she was told that I came from the same country as she was. This and other similar relevant issues will be discussed in detail under the section describing my position as a researcher.

I interviewed three interpreters who have experience of interpreting for HIV positive women. Initially I planned to recruit interpreters from www.tolkeportalen.no, the National Register for Qualified Interpreters. However, my previous work gave me the opportunity to cooperate with many different professionals including interpreters. Therefore, I used my previous professional network to recruit one interpreter, and my personal contacts to recruit other two interpreters. It was a coincidence that all the interpreters were males. In fact, I approached

both female and male interpreters to participate in the study and one woman interpreter agreed to be interviewed. Nevertheless, she could not make it to the appointments twice. Once the three interpreters agreed to be interviewed, we arranged appointments to suitable dates.

3.4.3 Recording interviews

All informants agreed to be recorded with voice recorder, and interviews held in English were tape recorded and transcribed word by word in English. The interview held in Amharic was also translated in a word for word manner as much as possible. Parallel to the tape recording, notes were also taken during the interviews. This was especially so for points that the informants were noticed to give more emphasis and show exceptional concern. When it was seen vigorously, body language and facial expression were also taken note of.

3.5 Ethical consideration

This study was approved by Norwegian ethical committee, and by Norwegian Social Science Data Services (NSD). The objective and purpose of this study were explained to both committees. Formal communication has been established with Aksept and UUS. The approval letter from NSD and Ethics committee was presented to Aksept before the center started to approach potential informants. The interview guide was sent two social workers at Aksept, and they checked the questions before the actual interview commenced.

3.5.1 Informed consent

An informed consent means that a competent individual makes a decision to participate in research, after she has received the necessary information; adequately understood the information; and who, after considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation. (Ruyter, 2009). The aim of informed consent is thus to secure information from an informant that clearly understands the aim, purpose and use of the research and the motives of the researcher.

An informed consent protects the informant from being misused by the researcher, or others that may benefit from the work. It thus safeguards the informant and at the same time limits the researcher from misconduct. The most important aspect of informed consent is protecting the right of individuals to decide on their own lives and that of their close ones. Individual consent derives from the humane notion that everybody is his own master, and should not be forced to give information against own will. The informed consent protects individual rights. And has a better chance of securing information that is relevant for the research than if it was acquired through coercion or manipulation. Informed consent not only aims to collect

information based on knowledge and adequate understanding of one's situation, but it intends to protect vulnerable groups and individuals from manipulation. When informants give such a consent means that they are well aware of the dangers or challenges involved in sharing the information with the researcher (Ruyter, 2009).

The target group in this study is particularly vulnerable and their consent thus was greatly emphasized. We have had situations in which participants withdrew from the study due to fear of disclosure and lack of trust. In the consent form it was made clear that participants could withdraw anytime they find it fit to do so. This kind of reassurance was significant for participants' sense of security/protection. Apparently, immigrant women living with HIV/AIDS are vulnerable, and are afraid of expressing their experiences due to fear of stigma.

Participants were informed clearly that this study is based on voluntary participation. The women got the consent form in English and in Norwegian before we started the interview. Those who could read English or Norwegian signed after reading it. Those who could not read English or Norwegian signed the consent form after their interpreter (the social worker with multi-cultural background) interpreted for them.

3.5.2 Data handling

All tape recorded data were uploaded into a personal computer that was password protected. Both the computer and data were inaccessible to any other person. Though all informants had given name that they wanted to use only for the purpose of this study, written information were kept confidential and inaccessible as well. Uploaded interview files were carefully listened to and transcribed.

3.5.3 Anonymity

For security, dignity and respect of informants, their names were not mentioned in the interviews. With consultation, all informants rather took fictive names that they wanted to use only for the purpose of this study.

3.6 My position as a researcher

The majority of the informants gave me a positive reaction because I am a woman, mother, immigrant, and African but some chose to distance themselves also due to these aspects. Thus my identity had both positive and negative contribution on the data collection process.

Some of the immigrant women informants said that they felt close to me because they share motherhood with me. We could talk about children and other aspects of being an African

immigrant woman in Norway. Some informants asked me questions, advices and assurances for some of their concerns. Many informants were worried about their immigration status, wanted my personal opinion. They would say, “*What do you think your self about this? You are an immigrant woman too*”. There were many occasions in which informants wanted me to confirm some of their responses by saying; “*hey... we Africans, you know what I am talking about, you are a woman*” They gave the impression that they trusted me and shared some of their inner concerns. However, I was careful not to comment or give advice on their personal problems. As a researcher, I had an obligation to be neutral and keep a balanced relationship with informants.

My identity contributed also to some uncomfortable situations among immigrant women living with HIV during the data collection. When we were recruiting informants at Ullevål University Hospital (UUS), a potential informant agreed to participate in the focus group discussion when the doctor talked to her. Since we were given a list of countries where the patients came from, I picked one woman from my own country. When we were told that the person has agreed to talk to us, I told the PhD student to go out and let her know my identity. The potential informant refused to participate in the FGD when the PhD student told her that I was from the same country as she was.

For few HIV positive women it was unacceptable that I was an African, but not HIV positive and still wanted to approach them and gather information. One day, after interviewing an informant at Aksept, I was invited to join the people for dinner. A woman from the same country as I am thought I was HIV positive woman and she came and sat close by and asked me, “Have you been coming here for a long time?” and further inquired if I have been HIV positive person for a long time and if I have visited the organization for a long time. She felt very comfortable to see me there and started to talk about her situation. Taking me for an HIV positive person, she wanted to share her experience with me. I then told her that, I was not HIV positive woman and that I was a student who came there to interview HIV positive women about their experiences on communicating with healthcare providers. The lady’s understanding was that the organization was only for HIV positive people and she did not understand why I was allowed if I was not HIV positive. Apparently she was not informed properly that the place was open for everybody three days a week. When we were eating dinner, she asked me, “Does it mean people who are not HIV positive can come here? But what if they go out and talk what they have seen here?” She was not comfortable of my

presence, and expressed it clearly. However, during our dinner I asked her if she would participate in the interview. The lady agreed and told me that I could call her and make an appointment. Two days later I was told that she was not interested to participate in the interview. I have experienced several rejections by potential informants as a result of my background, and due to their fear of exposing their HIV status.

I understood the reactions of these women, because I have also experienced the burden of HIV and stigma in my own family, relatives and friends.

3.7 Data analysis

After every interview, recorded data were listened to repeatedly, and then they were transcribed carefully. I read the transcribed data over and over again till I managed to capture the sense of the whole (Sandelowski, 1995).

Two of the interviews were done in a language I can speak, and the interviews were translated to English, and checked if all the information was taken by listening to the interviews and reading the transcribed information. After transcription and translation, all the data were categorized manually. Initially, I approached a software program NVivo 09, but after trying the program for a while I discovered that the program was not picking all the information I needed. Therefore I used my interview guide to categorize the data by highlighting with different colors. Since interview guide included many questions it was necessary to summarize the data again according to research questions which are;

- How do immigrant women with HIV perceive their communication with healthcare providers?
- Does the use of interpreters facilitate or hinder good communication between immigrant women with HIV and healthcare providers?
- Do immigrant women with HIV get enough health information?

When informants were being interviewed, it seemed that it was natural for them to give information that was broad, unstructured and long. However according to (Kvale 1996) long statements are compressed into briefer statements in which the main sense of what is said is rephrased in a few words. Thus I have summarized long sentences in shorter ones underlining the central points that relate to the research questions.

4. Findings

Introduction

The main objective of this study is to explore if barriers exist in communication between immigrant women living with HIV and healthcare providers in Norway. The findings in the study are primarily based on data obtained through in-depth interviews with immigrant women living with HIV, supplementary in-depth interviews with three interpreters, and a focus group discussion. Supplementary data was also gathered through discussions with two social workers at Aksept who are working closely with the informants. One of these employees has an immigrant background, and functioned as an interpreter during the interviews. She also played a significant role in recruiting candidates. The other employee also had a leading role in recruiting immigrant women. The conversations with both employees were carried out after their interviews with the immigrant women were finalized. The result of the conversations with these two employees will only be used as a supplement for the findings and will be presented in this chapter.

The findings will be presented in three main parts. The first part explores immigrant women living with HIV experiences with accessing information on HIV. This will start by giving a brief overview of the official sources of health information for HIV positive immigrants, especially for those who have arrived in Norway recently. The second section reviews informants' perceptions and experiences regarding communication with healthcare providers. The third section presents informants' experiences with using interpreters during communication with healthcare providers.

4.1 Accessing health information

Interviews with eight immigrant women living with HIV for in-depth interview and eight in the focus group discussion were initiated by asking them what they knew about HIV before and after they were diagnosed with the disease. The first reaction of the majority of respondents reflects their lack of information and limited knowledge about HIV. All informants except one had a dramatic and traumatic perception of HIV before they were diagnosed. They thought they were terminally ill. Almost all of them expressed feelings of shock and helplessness. Halma as one of the informants said that she got mad when she was told for the first time that she was infected with HIV. She wanted to kill herself, but she was worried that nobody would take care of her son if she died. She said:

I used to force myself to sleep so that I could forget the disease at least for few hours, but when I woke up it was still in me it was really stressful. It is disturbing me a lot. No matter what I do it remains with me. I can never forget it what I have, when I am sleeping, when I am laying down every day. I must know I am HIV positive. So I can not live free life the way I want anymore. It can never be the same. I am just thinking I will die.

All informants except two said they were surprised that they became infected with HIV virus. They did not consider themselves as belonging to risk groups, which, according to them, included prostitutes, gay people and others with multiple partners. For instance one of the informants, Dora thought that people get HIV only because of promiscuous sexual behavior,

I have seen many people who died of this disease, but me! I always had only one boyfriend. I was faithful to him, and I know he was faithful to me too. I knew this disease was for those who change partner often. I still have problem understanding what went wrong, this is a mystery.

Another informant called Princess was a married woman with three children discovered that her children and her husband are HIV negative. She maintained that her husband has always been faithful to her. Therefore, it was hard for her to understand the fact that she was infected with HIV virus. Both Dora and Princess believed that faithfulness in their relationship should have protected them from being infected with the virus. Dora said that since she felt she was not going to be HIV positive she never paid attention to information on HIV. Participants in the focus group discussion also mentioned that they still had problem of understanding why they became HIV positive, because they said they always behaved well and were faithful in their relationships.

In contrast, two of the informants, Kenzua and Vivian categorized themselves in the risk group and knew there was always a possibility for them to be infected with HIV virus. Kenzua said she had lived a very tough life, thus she had expected to be infected with HIV. However, when she took the test and the result confirmed that she was HIV positive, she said she was shocked. Also Vivian, another informant, said that she knew she might possibly be HIV positive before she was diagnosed. This was because Vivian had partners who died of

HIV and she was experiencing some of the symptoms her partners had before they died of AIDS.

The majority of the informants had little knowledge about HIV and its treatment prior to their diagnosis. They thought that having the virus meant a death sentence. They were unaware of the fact that they could live longer with HIV medication, especially here in Norway. Prior to their arrival in Norway they had limited information about the disease and available treatment. The informants lacked basic information about HIV, which would have made it easier to cope with the shock and frustration they had to face following the diagnosis. The informants that were diagnosed in their home countries said that they did not get enough information about treatment including the side effects of being on the medication and the necessary nutritional guidelines to follow while being treated. Those who know their HIV status in Norway stressed the importance of getting health information and reported some level of relief after getting more information. Aksept is the principal centre of information for most of the informants as it has served as the main venue where HIV positive people meet. Other information sources include refugee camps, the internet, and healthcare providers.

4.1.2 Information from Aksept

Aksept is the main source of health information for most of my informants and many other HIV positive people, who often meet there to commiserate and share their experiences. Informants expressed that they were comfortable when they talked to people in similar situations as they do at Aksept. Many believe that the information provided at the center constitutes the majority of their knowledge and understanding about HIV. Halma said;

Aksept is the best place to get information, I also learned from Aksept that if I want to have a child, I can have one and the child won't be HIV positive. The first time I came here at Aksept and saw a pregnant woman, I was surprised. Now I know it is possible. When I am alone I go crazy, but coming here and using the services, and most importantly laughing with others is great.

Also Vera who was also getting information from Aksept said;

For me the best way of getting information is talking to people who have the same problem. That is why Aksept is the best place for me to talk about HIV. I know they understand me.

Although the majority of informants reported Aksept to be the best place to access information, there are still many other HIV positive people who prefer to not go there due to the stigma involved with being seen at this facility. Informants said that they knew some immigrants living with the virus who choose not to visit Aksept because they do not want to be identified as possibly having HIV. The information obtained from an employee at Aksept further attested to this situation. She knew many HIV positive immigrants who get services in places other than Aksept as a result of their anxiety about being seen at the center. It is also worth noting here that those HIV positive people who live far from Oslo cannot benefit from the services at Aksept. They have to depend on other information sources such as healthcare providers, the Internet, books, booklets or other organizations.

Aksept does not provide HIV positive people with medication. However, it does provide basic treatment such as changing catheters and changing bandages, and also provides some acute emergency help. The center has its nurses on duty the whole day but physicians are not available in the evenings or at night. However, with regard to information provision for HIV positive people, Aksept invites specialists to the center whenever the need arises. Also, Aksept has contact with many different professionals, such as psychologists, who are directly involved with HIV positive people. It also arranges settings like women and men support groups and Christmas and summer garden parties.

Patients may be admitted to Aksept for inpatient services for anywhere from three days to two months depending on their needs. These services are primarily meant for HIV positive people who are in Oslo, but those who live outside of Oslo can be given in-patient care at the center if they are in a critical situation.

4.1.3 Information at Refugee camps

HIV positive asylum seekers are provided with leaflets that have basic HIV information. In addition, they speak with a nurse at the refugee camps, and they can be referred to Aksept if they do not live too far from Oslo. Information about HIV is not provided in all refugee camps, but some refugee camps have days in which the health professionals talk about various health issues. After this general information session, the health professionals offer needs based individual consultation for the asylum seekers. In that way, HIV positive immigrants also have the chance to enjoy professional consultation regarding their individual issues and concerns. All of the informants in this study, other than one, are asylum seekers, and five of these informants were living in refugee camps. Some said they were satisfied with

the information they received there. However, it was difficult for them to enjoy the consultations to their fullest because they often feared that other camp mates would notice their receiving information about HIV.

4.1.4 Information from the Internet

Getting information from the Internet seems to be safer to some of the informants who are using internet as a source of information. In addition to the information facilities at Aksept, Halma used the Internet to access information;

I also get information from internet; this is good because no one will know that I am reading information about HIV. I know people who are getting information do better than people who are not.

All of the informants who had internet access considered the internet as also the best way of getting information on HIV medication and its side effects. This was followed by information from healthcare providers and sharing experiences with people in the same situation. They felt that they can use as much time as they need and find the necessary information they seek. They also understood the internet as a safe way to get information without exposing their HIV status to other people. During the focus group discussion participants were pointing out what type of information they have generally read on the Internet. Accordingly, some of them came into contact with content claiming that there is a cure for HIV, but it is not meant for everybody. They read that there was a tablet in Germany which they could take once, and could wait for year before they take medication again. This type of information seems to provide them hope for their future. However, owing to their lack of access and low level of computer literacy, as well as poor mastery of language, not all informants interviewed were able to use the Internet.

The National Institute of Public Health has posted on their webpage basic information about HIV in 20 different languages, among which 5 are African languages. The information describes what HIV is, how it is transmitted, how one may protect himself or herself from it, and how it can be treated. It also contains information on HIV testing, dealing with test results, and other important items. The organization, “HIV Norway” also provides basic HIV information. However, not many immigrants are aware of these provisions by the organization.

For those who can access information from internet and who are not hindered by language incompetence, the internet has been indeed a useful source of knowledge regarding HIV and related health issues. Using search engines such as Google and Yahoo, informants stated that they often limited their search topics like side effects of HIV drugs, nutrition, medication, new developments in treating HIV, etc.

4.1.5 Information from healthcare providers

HIV positive people go to their doctors for follow-up depending on their condition. This means, if the HIV positive person is in a good condition, the person does not need to see his/her doctor very often. Nevertheless, the usual protocol is that patients see their doctors once every three months, but if the HIV positive person is in a very good condition he or she might need to see the doctor once in six months. Hence after three months of waiting, people living with HIV go to their doctors with the expectation of getting good information about their health. However informants reported that the information they got from doctors is very limited. Many informants said that doctors do not provide them with information they need when it comes to their HIV status. Suz was one of the informants who were not able to use the internet to access information on HIV. She has been living with HIV for 8 years, but she felt she did not know enough and did not get as much information about the HIV medication and its side effects as she would have liked;

I never got information about HIV, the only information I got from my doctor is just what my blood test turned out to be and how I am doing- like that I am okay. Other than that I do not get information about HIV medicine, side effect and food. But it would have been helpful if I got more information from my doctor and in my own language in the form of booklets and leaflets.

Suz and many of the informants are concerned about the side effects of their medication. They also want advice on nutrition so that they could fight certain side effects. Not knowing about side effects has been reported as a major problem for informants. The majority of the participants in the focus group discussion, as well as in some of the in-depth interviews, thought they were going to die each time they experienced side effects from their HIV medication. One of the participants in the FGD said each time she felt some pain or a reaction in her body; she always associated it with her HIV status, and was afraid that she might die. P5 expressed her fear of developing side effects as follows;

I wish the doctors knew what kinds of side effects can be expected and what the solutions are. For example, if they could say, 'if you have this side effect you should use this medication'. But here I don't know if it is the system. They don't tell you anything. They decide everything for you and they tell you that you have to take this medication. I wish they could include me when they make decision on my health.

This view is also shared by other women as they were of the opinion that they the doctors did not give them enough information that would help them understand the side effects of ARV and their overall medication.

Dora was diagnosed with HIV four years ago in Norway, and she had not started HIV treatment at the time of the interview. She did not know why she had not started the treatment. She seemed very confused, and wondered if she was HIV positive at all. What the doctors told her so far was that she was a special case. Dora had been asking her doctors many times what they meant by special case, but the doctors were not willing to give her a clear answer;

I have been asking my doctors many times if I am sick, but they still cannot answer me. They keep saying that I have special case. What is special case? Nothing is clear for me.

Dora felt that the doctors were treating her as worthless. She felt she was not being given the right information. As a result, she was confused and uncertain about her HIV status. She said that, when men approach her for a relationship she does not know what she should tell them, since she was not sure whether she was HIV positive or not. Dora is confused because she has been diagnosed with HIV, but has not started the treatment yet for unknown reason, and therefore Dora is unsure of her status.

Informants are very vulnerable, but according to most informants doctors did not seem to understand what they are going through. Thomas, one of the interpreters, expressed his observation regarding patients getting HIV information from doctors as follows;

To be honest, patients don't get that much information. Most of the doctors, when they meet patients, they just talk and talk and they ask the patients if they understand. Of course the patients need time to digest all the talk the doctor did, and won't be able to

ask question there and then. That is why most of the patients reply “no I don’t have a question

Information from doctors is important for their patients, but is also important that doctors know when to give information to patients. Information given when a patient is distressed directly after hearing that she is HIV positive will not be received as intended. Such immediate disclosure of information that is technical and complicated, particularly at a time when the patient is emotionally fragile and shocked is highly difficult for the HIV positive person to understand.

Informants in this study almost unanimously expressed the need for doctors to give them the necessary information about their HIV status. They felt that doctors were not providing them enough information in a manner they understand. Although the other resources for information are appreciated by informants, many of the resources have their own challenges to be accessed. Hence information from healthcare providers was deemed more suitable and reliable if it is provided adequately.

The next section will present the findings on the perception and experiences of immigrant women living with HIV with regards to their communication with healthcare providers in Norway.

4.2 Communication with healthcare providers

Good doctor-patient communication ensures the proper provision of information on medication, laboratory results, diagnosis, side effects and advice to patients. It involves effective dialogue between the doctor and the patient whereby patients are allowed to take part in the decision making process with regard to their health. It also prerequisites mutual respect.

Informants strongly expressed the importance of good communication with their doctors. They feel that doctors are the ones who know more about their health, and therefore having a good relationship with them is of paramount importance. Those informants who have a good relationship with their doctors seemed to have hope and a feeling of optimism. Many of these women initially felt they were going to die when they got the news of their HIV status. Therefore doctors have played important role in their present lives which, unlike the past, they have learned to cope with their disease without despair. A participant in the focus group

discussion (FGD), P4, expressed her experiences of communication with her doctor as follows:

My doctor told me that I will not die of HIV but I will die of some other disease, maybe by then I am 60. I will be very happy if I live up to 60.

Another FGD participant, P6 stated:

My doctor is a very nice man. He encourages me. He tells me that there are many African strong women; he knows that I will make it.

Kenzua spoke limited English but prefers not to use interpreter while speaking with her doctor. Yet she was happy with their communication. She said,

Communicating with my doctor is my life. I can not hide things from him. If I hide from him that means I die. I am very free with my doctor. I speak little English and I use that to talk to the doctor; the doctor has told me that I am in good condition.

Immigrant women living with HIV get encouragement from their doctor's comforting words. Many of the informants had a traumatic perception of HIV. Thus, when their doctors told them that they are not going to die prematurely, they became optimistic about the future and this in turn helped them to have positive attitude towards themselves as HIV positive individuals. It is clear to see a marked difference of such attitude between informants who claimed to have a good rapport with their doctors and those who did not feel they have that sort of relationship. Informants who said had good relationship with their doctor seem to cope with the disease well, whereas those who reported negative experiences appeared to struggle the most. Informants, who have been given care, good explanations about their medications, including their side effects, are those who seemed to have developed a sense of self-worth and positive attitude towards their situation as HIV positive people.

The procedure for HIV diagnosis in Norway differs from those followed by the healthcare services in the countries where the informants come from. People diagnosed with the virus receive continuous, needs based comfort and support by professional nurses. One HIV positive person usually has a nurse who she or he can talk to in order to get emotional support. As Princess said:

The nurse is there for me 24 hours. I can call her at her work or her mobile number. The nurse boosts my confidence. She tells me about the development of the HIV medication, how many people have managed to live for many years. She gives me different picture about HIV than I had in me for many years. Now I have realized HIV is not that bad. I can live for many years; this is because of the nurse. She sits with me; talks to me; provide me with leaflets, condoms, and tell me in a good manner that I should use condom when having sex with others. I don't feel bad because she is telling me to use condom, she is giving me information in such a way that she respects my feelings. I am not the only one who is happy with my nurse. I have talked to my friends who are HIV positive. They feel the same way about their nurses. The nurses are very well trained, and have a good understanding of the disease.

According to the above informant, the nurse plays important role in providing counseling and information. This statement also shows that princess has frequent contact and good relations with her nurse, who helps her to cope with her everyday stress.

Another informant, diagnosed in her home country, said that nurses have little role to play during follow-ups and treatment. This might be because they already knew they are HIV positive before their first doctor visit here in Norway, and the needs for emotional support might not be as strong as those who are diagnosed here in Norway and for whom support has been at their disposal from the start. As Kenzua said:

I don't normally have long conversation with nurses. The only thing they do for me is just make appointment for the next visit according to the paper I give them from the doctor, and when I come to see my doctor, they tell me to sit and wait. This is what we converse. Not much.

However, the majority of the informants have expressed dissatisfaction with their communication and relationship with their doctors. They lamented about the insufficient information regarding side effects, the limited time they have with their doctors, and the health care providers' lack of respect for their patients. Some of the informants also reported that they were made to see different doctors on various occasions and that has not enabled them to establish a fairly stable and good relationship with just one doctor.

Halma, speaks fluent English, but she feels the communication with her doctors was often inconsistent. She said that despite her initially very good interactions with doctors who

assured her that she was going to be fine, the communication situations have changed over time to the extent that the doctors gave her little time to explain her conditions.

Also, Princess asserted that, even though she speaks fluent English, good communication was not only about the language fluency but also necessitates mutual respect. She felt that the doctors she met never treated her well and she was not given the information for which she asked. Here is what she had to say:

You come here and find out that your white blood cell maybe 800. It may be 500 after three months and this guy will still tell me it is fine, and I know the number of my blood cells has dropped down. Sometimes I asked him, 'my blood cell level has dropped from 800 to 500, how come that you are telling me it is good?' Although I know 500 is good, but it has been a drop and my question is why has it been so? He does not bother

Princess's experience shows that her language fluency did not influence the way she and her doctor communicate. Demand for details of her medical situation and knowledge of what her treatments entail have not been met.

Informants seemed to be vulnerable and need care and respect during doctor-patient consultations. It would help informants build trust with their doctors, which in turn helps them to cope with their disease in a more positive way. One way of building trust in their interactions with doctors is by having a steady relationship. It is easier and more comfortable for patients if they have one doctor who they meet with regularly for their treatment and follow-ups. Informants reported that engaging with many doctors causes poor communication and creates a lot of stress for them. Vera, for instance, said:

It was only the first time I had a good doctor. And when they changed her I cried. When I was talking to her she was listening, she would seat with me and explain everything. That felt good she respected me. Now they are changing doctors just like they are changing interpreters. No one knows about my problem, I tell my doctor about my problem today and he goes away, and another one comes and starts explaining to the new doctor all over again. I told the doctor that I don't want to explain my problem again, as I did explain to the first doctors. Because if I keep explaining my problem to everybody what is the use. I am tired I don't have energy.

Dora has come into contact with many doctors as well and she did not feel she got clear information from all of them about her HIV status. She complained,

I meet one doctor today and I meet another one tomorrow, and all of them are telling me different things. I get confused.

Vera, Dora and Jaquaty were all of the opinion that just one doctor be assigned to them would lessen the great stress they suffer from dealing with many doctors. In addition, they would also avoid explaining similar accounts of their situation several times to various physicians. They could establish a good relationship with their doctors and benefit more from their meetings. Another issue informants complained about was the lack of adequate time during consultations with doctors. The next section will address the stigma felt by informants with regard to their perceived treatment by healthcare providers.

4.2.1 Stigma by healthcare providers

Although stigma was not a central theme for this study, informants mentioned it repeatedly and therefore I felt it is necessary to discuss. Informants stated that because of fear of stigma, they are often reluctant to access important and available health services with confidence. Suz, Princess and Dora all felt stigmatized by their healthcare providers because they are HIV positive. Suz said that, when she had appointment, the doctor did not receive her immediately. Waiting for over an hour to see her doctor was a very common experience and she believed that it was not because the doctor was busy, but because she was valued less due to her HIV status. She had the following experience when she visited a dentist:

Once I had a toothache and went to a dentist. The dentist looked at me and said he needs to remove one tooth. And after few minutes, that is after he read my form where I wrote down I am HIV positive, he and his assistant left me in the room, and they came back after a while. When they came back they told me that they could not help me that day. They said that I should take an antibiotic that was going to take many days. For me waiting one more minute felt like hell. Therefore, I went to another dentist and I did not write that I was HIV positive this time. Then he removed the tooth, and I got better. This kind of discrimination makes me communicate less with healthcare providers.

For all three informants the core source of the stigma they receive is from the healthcare providers themselves. Dora's impression, for instance, was that people who are working at the hospital are afraid of HIV positive people. She said:

They are afraid that they may get the HIV virus from you. I don't get any respect from the hospital workers? But here (Aksept) they even give you massage, and they don't show you that you are a sick person. No one is afraid of touching you.

Princess was admitted in the hospital after being diagnosed with HIV and she expressed her experiences at the hospital as follows:

..... If you are HIV positive you do not get the same treatment in the ward. No body comes and talks to you; they don't even check how you are feeling. The only thing they are good at is, making the whole environment curious for visitors. For example, when you come to the room, you notice everything is red. And in the other room you have black plastic bag and people will notice there must be something that they have used red plastic for. It will be very noticeable for visitors; I think all these can be seen as stigmatizing. If they had talked to me, I would have given them a good help. I studied science myself and I know how things work.

Princess felt mistreated in the hospital and not happy that her room was different from other rooms in a way that was noticeable to others. She complained there was no need to publicize her HIV status.

Informants expressed their experiences of stigma from both healthcare providers and others. They particularly underlined that being stigmatized by healthcare providers affected their relationship with them. This greatly contributes to poor communication between healthcare providers and their patients.

4.2.2 Cultural barriers with communication

Informants considered cultural barriers as another factor limiting their communication with their healthcare providers. Many of the informants feel that the doctor should take the initiative to talk to them and also understand their multiple problems as HIV positive people. This is what many of them are used to in their home countries, where the doctors have the power to decide all things with regard to patient care, and patients have limited involvement in their own health matters. The cultural background of the patients, therefore, made it

difficult for them to understand and appreciate the approach of doctors in Norway which gives room for patients to have a say in their treatment. A participant said:

He is a doctor he knows what my problem is; I don't know what my problem is. If I knew I would have treated myself at home. Why bother?

The informant in this case gives the whole responsibility of her care to the doctor. She expects the doctor to know about all of her problems and to help her without her active participation in the sessions with him. This is a cultural gap regarding expectations between immigrant patients and Norwegian healthcare providers. An interpreter also commented on the cultural differences between African immigrant patients and Norwegian healthcare providers. He said that many African women are influenced by their own culture and their educational background. Thomas and Mick said that it was rare that they experience effective two way communication between immigrant patients and Norwegian healthcare providers. For them the communication is only one way, trickling down from doctors to patients. In many cases it is only the doctor who talks and the patients do not respond. The two interpreters said that one reason for such communication might be that in many African countries patients are expected remain quiet and just to listen to what the doctor says. Another reason, the interpreters further asserted, can be that doctors are professionals and due to this feel they have all of the power. As a result, patients might view the doctors as an absolute power and they therefore do not dare to open conversation with them.

4.2.3 Language barrier

Communicating without a common language and without a language assistant can be difficult for both parties. Therefore it is always important to make sure an interpreter is available when communicating with patients without common language. The finding here shows that informants without common language and who have not been provided an interpreter have great difficulties with explaining their situation as well as understanding the information given to them from their doctors.

Informants had a varying level of English language proficiency. Halma, Vivian, and Princess speak fluent English, whereas Dora and KENZUA speak some English, and Jaquaty, Suz and Vera speak very little English. Sometimes the women used interpreters to communicate with their healthcare providers. Three of the informants in the focus group discussion spoke fluent English while the rest of the group used interpreters.

Informants reported inadequate use of interpreters during their encounters with healthcare providers. Some informants said that they were not always provided with interpreters and were often forced to use their broken language to talk to their doctors. Dora, who had language limitations in communicating with doctors properly said:

My doctor tells me that he will see if he can get me an interpreter but, most of the time, he talks to me without interpreter. He knows I don't understand everything he says. I need to be listened to, but when I know he will not understand me I don't talk. What can I do? I understand only half of the things the doctor is telling me and I am not sure how much he understood what I told him.

A participant in the focus group discussion who did not get the chance of using an interpreter when communicating with healthcare providers said,

I need translator every time I go to the doctor, because of the language problem we cannot communicate. And I don't have translator therefore I try to understand what I can. And what I can't is left like that, because of the language. (p 3)

Another participant said:

I cannot tell the doctor everything I wanted and I don't always or most of the times understand what the doctor is talking about. (P 5)

The above statements show that immigrants living with HIV often have to struggle to communicate with doctors due to language barriers. The informants do not understand what the doctors tell them. This shows clearly that there is a gap between what the doctors try to communicate to them and what the patients understand. The informants seemed to feel powerless to ask the doctors for clarification and tend to sometimes leave the sessions with insufficient comprehension of what the doctors tell them. The results of this study also revealed that many doctors meet their immigrant patients without interpreters. The lack of adequate communication can cause deep misunderstandings between the doctor and the patient. Thus most informants state that the use of interpreters is a key to their communication with doctors. However, informants had varied experiences with their use of interpreters as well. The next section will look at informants' perceptions with regard to the use of interpreters during their communication with doctors.

4.3 Use of interpreters

In this study, five of the informants who participated in the in-depth interview and five informants who participated in the focus group discussion needed to use interpreters when meeting with their doctors. Informants expressed their views about using interpreters. All informants who use interpreters are happy they are able to communicate with their doctors through interpreters. However informants are reluctant to use interpreters from their own countries, which cause a problem in finding interpreters with the necessary language skills.

Dora spoke limited English and she knew that she was not able to explain her problem to her doctors the way she desired. She explained;

I am happy an interpreter is helping me when I talk to my doctor, because when I have questions, I know that the interpreter will ask for me, when I don't have difficulties to do that myself. When I have problem or question I try to directly tell my doctor but it is difficult. And sometimes I see it from the doctor's eye that he does not understand after I finished telling him. So many times I prefer not to say anything. I know the doctor listens to me better when I use an interpreter. And I feel ascertained that all the information the doctor gives, I get it through the interpreter. In that way, I feel alright.

Vera also thought it is ok to have interpreters when she talks to her doctor. She said;

The interpreter helps me to tell my problem to the doctor well. He also explains very nicely things about my health, and that is important.

For many people, explaining health issues without language fluency is quite challenging. Thus informants attach a huge significance to the use of interpreters in their communication with doctors and nurses.

Interpreter informants regarded their skills as very important for the patients as well as for healthcare providers. All three interpreters considered their role as a bridge between two persons who wouldn't have communicated well without them. Interpreters also believed that they do their job professionally, carefully, accurately and with a sense of responsibility.

One big concern in the use of interpreters, however, is that while immigrant women with HIV are aware of the importance of using interpreters, they still fear disclosing their HIV status to interpreters from their own countries. They fear that the interpreters might not respect their confidentiality, and, as a result, tell their HIV status to other people in their own immigrant

communities. Many of the informants also find the use of interpreters in medical situations as a novel experience because it is not common in their home countries. Thus, they struggle to get used to the idea of trusting and using interpreters. Overall, informants have reported the mistrust of interpreters keeping confidentiality, and the use of various interpreters instead of one, consistent interpreter, to be the two primary barriers to them utilizing interpreters during their encounter with doctors in Norway. These two primary barriers are discussed in the following two sections.

4.3.1 Mistrust of interpreters

For many of the informants HIV is a deadly disease, and is associated with practices such as promiscuity and prostitution that are unacceptable in the society's form which they come. Thus, they are afraid to talk about HIV openly in front of an interpreter from their home country. Jaquaty can speak neither Norwegian nor English when she is communicating with healthcare providers. Therefore she is dependent on interpreters. Here is her view of using interpreters;

I have a need for interpreters, but using an interpreter from my country is not good. This is because of the disease "HIV" which leads to stigma among us. I prefer to use interpreters from other countries who understand my language. When I see interpreters from my country, I change the topic. I don't say what my problem is. I tell them something different. HIV is a big problem in my country. If people from my country know that I have HIV, they don't see me like a human. It is bad. So what I do is if the interpreter is from my country, I ask a different question. I don't say everything in relation to HIV. I know this is not good, but what can I do?

Though Jaquaty knew the importance of using interpreters, she was scared about what people from her country would say if they knew that she was HIV positive. For this reason, she changes her question in front of an interpreter from her country, asking her doctor a wrong question and going home with the wrong information. She added that she always prayed that her doctor would provide her, at the next appointment, with an interpreter who is not from her own country. This can pose a big problem. HIV positive people need close follow-up, and they may also have important issues that they need to discuss with their doctors. Shying away from telling their doctors the truth about their condition and questions massively hinders the communication and endangers the whole package of the treatment.

Dora is another informant who had to use interpreters, and she acknowledged the importance of using interpreters when she is communicating with her doctors. But she seemed to have a problem using interpreters from Africa, she said as follows;

I am not always happy to use an interpreter when I am not sure where the interpreter is from. For example, you know the people from Africa. After doing her or his job he will go out and tell about you, you know? Because of that you don't feel like being open, no one wants to be in this situation of course; it is my secret. When I go somewhere, people will start saying, 'Look at this woman. She is sick; she has HIV', this is not good. And this happened to my friends. Therefore, whenever I get the chance I tell the doctor that I do not want interpreters who are from Africa. I don't know, but if the people are from my country, maybe they know me. So I always say I want white people, I don't want interpreters from Africa.

Dora's fear was rather different as she was uncomfortable not just with interpreters from her own country but also with those from anywhere in Africa. This poses difficulties because many languages are not spoken widely across nations, so the chances of finding interpreters that speak their language yet are not from their country, or continent even, are limited. Except one informant, all the others who are using interpreters said that they would like to use interpreters from countries other than their own. They feared that interpreters from their own countries might tell their HIV status to other fellow immigrants, and destroy their reputation, since the news might contribute to their isolation from friends and fellow countrymen.

4.3.2 Using various interpreters

The majority of informants encounter different interpreters each time they go to their appointments with doctors. Informants complained that using different interpreters increases the chances for their HIV status being known by many people in their community. This situation creates mistrust towards interpreters and limits their communication with the doctors. Suz is one of the informants who used interpreters and she explained her unease of using many interpreters;

Yes I use interpreters, but I don't feel comfortable with using interpreters. This is because I get many different interpreters. Since I live in small town, having many people as interpreters is just letting everybody know about my HIV status. I have been told that interpreters do not tell patients' history to others, but when I see them in

town or at any social gatherings, I feel embarrassed because I know that they know I am HIV positive. I am not as healthy as they are, and that does not make me feel good and I feel very small inferior. I would prefer to have only one person as my interpreter, and I have told this to the doctor very many times. But that is not working.

Mick, one of the interpreters, worked as interpreter for four years and shared Suz's concern. He said that in his culture sick people are seen as incapable of functioning in normal life. Therefore, when patients sit between a doctor and an interpreter and seek help from the interpreter who is from their country, the patients feel ashamed. Thus, they choose to be less open and do not want to tell all their problems. Mick said that as an interpreter, he always did his best to create a good atmosphere for the patients to feel more at ease than ashamed.

Thomas is another informant who worked nine years as an interpreter. She also shares Suz's concern of living in a small community and being noticed by people to whom she has disclosed her HIV status. Thomas said;

Most living with HIV live in small communities. And people meet in different common places, like for instance, parties in which their known HIV status could make them very isolated. That is why it is very important to keep the professional role of interpreting, like not saying anything to anyone. The other thing is to make them feel that you don't remember them and most of the time, you don't remember who you interpret to, but they can remember you. I personally try to avoid them especially when I see them at a party and places like that.

According to Thomas, it is tough even for interpreters to maintain their relationship with HIV positive people in social gatherings. All three interpreter informants share the HIV positive informants' concerns those interpreters might disclose their HIV status to their respective immigrant communities, although they maintained that they personally never did so.

Informants living with the HIV virus worry that if they keep disclosing their HIV status to many interpreters, many people will soon know that they are HIV positive. Because of this fear Vera, for instance, said that she cancelled one of her appointments with her doctor when she saw an interpreter who she had not seen before. The interpreter informants also understood HIV positive women's fear of using various interpreters during their medical appointments.

Having one interpreter for one patient is reported to be the best solution for doctor-patient communication. However, Mick, who is an interpreter, is not sure whether it is realistic to assign only one particular interpreter to a particular patient. He said;

It is not practical to assign one interpreter to one patient. The agency might have many interpreters and the interpreter who assisted a particular person might be sick or may not be able to show up for some reason as needed. Therefore, they have to call another person. But, I still agree continuity is very important. . I know many people want to use only one interpreter this is because the patient does not need to worry how many people know about his or her situation. It is more likely to build trust with one person than more. However, there may be a need to change interpreters if they fail to do their job properly and if their communication with the patients is troubled one way or another.

Indeed, as explained by Mick, although it is preferable to use one interpreter for one patient, it is also good to change interpreters in case where the communication between the interpreter and patient is not adequate. Using one interpreter is challenging and costly, but it might help patients to develop more trust with them and thus with their doctor as well.

5. Discussion

This study was conducted to understand HIV positive immigrant women's perceptions regarding their communication with healthcare providers, to explore their experiences with accessing health information, and to determine their feelings about the use of interpreters during their medical visits. The findings of this study reveal that there is a lack of communication between healthcare providers and immigrant women living with HIV causing less than optimal medical visits.

5.1 Access to health information

The study found that there are three main factors hindering HIV positive immigrants from receiving proper healthcare information: lack of health knowledge, fear of stigmatization, and limited consultation time with their physicians.

Giving proper HIV information to patients is complex and healthcare providers must be able to provide full health information and ensure the information is understood by patients. Patients' comprehension of health information is positively associated with patient satisfaction (Lukoschek, et al., 2003). Immigrant women living with HIV reported that information about HIV/AIDS is essential to avoiding the development of infection (AIDS). The primary information need for immigrant women living with HIV in this study is knowledge about medication side effects, nutrition, and CD4 levels (counts), and the implication of these on their disease. Informants had limited information regarding medication side effects, and are worried about the consequences of taking the necessary medications. As a result, when they experienced side effects, they felt their health was deteriorating and they were going to die.

The majority of informants in this study were asylum seekers, and few of them spoke English or Norwegian. Many of them live in refugee camps. Their main source of information is Aksept, where they not only meet with physicians, but also meet other immigrants with HIV. In addition, they get information at refugee camps and on the internet. Websites such as "HIV Norway" and the Norwegian Institute of Public Health website give basic information on HIV prevention and treatment. Some of the information, such as the right for free treatment and

information regarding the law that protects against discrimination are directly relevant to immigrants who are living with HIV/AIDS.

However, a lack of language fluency and the resultant inability to comprehend available information can reduce their ability to cope with HIV. Therefore, getting information from doctors is preferable among the informants in this study. O'Grady (2008) confirmed that people living with HIV/AIDS prefer person to person conversation with healthcare professionals as their primary source of information, rather than computer-mediated communication (CMC) (O'Grady, 2008). Other international studies also show that the most preferable source of health information for multiethnic minorities is healthcare providers (O'Malley, et al., 1999). However, informants in this study are not satisfied with the level of information they get from healthcare providers in Norway. Therefore they rely mainly on information from Aksept as well as information they receive from other immigrant women with similar experiences, which helps them to cope with stress and worries.

5.1.1 Lack of health knowledge

Miscommunication and misinterpretation often occurs with immigrant patients unfamiliar with medical terminology, limited health knowledge, and lack of local language fluency (Lukoschek, et al., 2003). In this regard, patients' educational level was found to be the most significant socio-demographic factor, followed by language barrier, and is associated with inability to understand health information. Less educated patients with limited language fluency are less likely to understand words used during health information delivery. Even if they recognize and interpret the words correctly, patients can have difficulties grasping the underlying concept. In this regard, doctors with a positive attitude about the importance of health information delivery to patients contribute to increased patient comprehension of health information. Thus, doctors need to be aware of patients' educational, language, and cultural barriers that may hinder comprehension of health information. It is important that doctors spend adequate time with patients to overcome those barriers (Lukoschek, et al., 2003).

Many of the informants in this study had limited knowledge about HIV prior to being diagnosed with it. A lack of knowledge about HIV/AIDS and medication contributes to psychological pressure during the first phase of HIV diagnosis (Kleven, 2006). Some of my informants had difficulties getting treatment for HIV and accessing medication in their home

countries. Thus, it took them sometime to understand that it is different and easier here in Norway than in their home countries.

5.1.2 Fear of stigma

Fear of stigma significantly reduces a HIV positive immigrant's ability to access health information, due to fear of exposing their HIV status to family and friends (Anderson & Doyal, 2004). Informants in this study stated that they are afraid to search for information at home or other places where there are risks of exposing their HIV status. Some choose not to keep information material in their residences due to fear of exposing their HIV status. This fear is heightened among those who live in refugee camps, because immigrant women who live in refugee camps share bedrooms/residence with other asylum seekers. They have difficulties keeping secrets from cohabitants. This fear again impairs their ability to acquire information. My informants noted that was one of reasons they prefer to visit Aksept, because it allows them to exchange information without exposing their HIV status. Thus getting information at Aksept makes it easier to hide their HIV status from others in the refugee camp.

5.1.3 Limit of consultation time with doctors

According to the informants in this study, having limited consultation time with doctors reduces the amount and quality of information they are able to acquire. Informants meet with doctors every three months, for approximately 20 minutes per visit. For many informants those twenty minutes are too short to fully discuss their needs and concerns, particularly in light of the language barrier that is often present. It is difficult for immigrant women living with HIV to comprehend the complexity of HIV virus, and its medication, cd4 count, and side effects. When they go to the doctors, they prepare to ask questions about: their recent CD4 count and its implications; if there are any new and improved medications available; side effects of medications; and what kind of food they need to eat to cope with the strength of the medication.

In addition, they have other problems/concerns such as obtaining residence permits, employment opportunities, family responsibility, language difficulties, cultural differences, and others (Karago-Odongo, 2008a). In addition, they are marginalized, and have limited social contact. They seek advice and need to share their worries. Healthcare providers are among very few people immigrants living with HIV can openly discuss about their situation (Ndirangu & Evans, 2009). Therefore they look forward for an intimate and open

conversation with their doctors. The twenty minutes allocated for the consultation might not be enough to discuss these issues mentioned above. In addition, the language barrier makes the conversation difficult, and makes the time allocated even less adequate as doctors are unable to translate all of the pertinent information in such a short period.

5.2 Doctor-patient communication

Good communication between the doctor and patient is vital to the patient receiving good treatment (Lukoschek, et al., 2003). The majority of informants in this study described their communication with healthcare providers as inadequate. They expressed that their communication was very poor and they feel that their doctors want them to simply listen and follow instructions without expressing any opinions, desires, or concerns. Informants have identified the following barriers that hinder communication with healthcare providers: stigma by the healthcare providers; language difficulties; limited time with the doctors; feeling inferior; and lack of qualified interpreters that are not from their country or community. The barriers mentioned here are similar to the communication barriers mentioned in other studies on communication between immigrant patients and healthcare providers (Anderson & Doyal, 2004). These barriers contribute to the communication gap between Immigrant women living with HIV and healthcare providers.

5.2.1 Stigma by healthcare providers

A study by (Carr & Gramling, 2004) showed that healthcare providers were among those who stigmatize immigrants with HIV/AIDS. Many of the informants in this study stated that they have experienced discrimination and stigma by healthcare providers. Three of the informant gave examples of their experiences of being stigmatized by healthcare providers. The experiences from informants reminds us that healthcare providers need to be conscious of their own stigmatization of HIV positive patients, and need to give emotional and psychological support for people living with HIV.

Other forms of discrimination also factor into poor doctor-patient communication. A study in the USA showed that factors such as (among other things) ethnicity and appearance influenced physician behaviors with their patients. Physicians rated higher on information giving and emphatic skills when they were with patients of European origin (Graugaard, 2003) Another study by (Schouten, et al., 2005) showed that doctors engage less in social talk and are less friendly with minority patients compared to white patients. These points have been identified by a majority of the informants in this study. Immigrant women complained

that they do not get enough attention from their doctors because doctors do not have respect for them.

Experiencing discrimination and feeling stigmatized has various negative consequences for HIV positive people with regards to their behaviors and attitudes. These consequences include fear of seeking health services, not adhering to treatment, becoming paranoid, and becoming fearful of disclosing their HIV status to sexual partners (Anderson & Doyal, 2004). Stigmatization from healthcare providers can scare HIV immigrant woman and hinder communication with them. According to Schouten, and Meeuwesen, (2005) ethnic minority patients are less verbally expressive, less assertive and less effective during medical encounters than white patients. Interpreter informants in this study also confirm that African immigrant women are less expressive during conversation with their doctors (Schouten, et al., 2005). Stigmatization by healthcare providers will make immigrant women with HIV even more fearful and less expressive.

5.2.2 Language barrier

For immigrant women in this study, the language barrier is the main obstacle hindering communication with healthcare providers. In doctor to patient communication a patient needs to adequately describe her symptoms to a caring physician, and the doctor in turn needs to explain the diagnosis and, treatment or prevention plan. The patient must understand and endorse this plan (Lukoschek, et al., 2003). The patient and doctor need to understand each other well in order to communicate such detailed topics properly (Emine Kale, 2006). The informants in this study felt that they were not able to explain their problem adequately to their doctors due to the language barrier present and the lack of caring on the doctor's part. They also said that they didn't always understand what their doctors were explaining to them. Most informants said that they were unhappy about their communication with their doctors.

Most of the informants in this study have limited understanding of the information they receive from their doctors, particularly since they rarely receive information through interpreters. As a result, they usually listen to what their doctors tell them passively, and have limited understanding of what they are being told. Due to limited consultation time with doctors they struggle to describe their symptoms properly and also to understand information they receive from their doctors. For example, an informant in this study was diagnosed with HIV four years ago but had not yet begun the treatment at the time of the interview. She said that she was not informed clearly about why she had not started treatment. She expressed her

frustration over not getting clear information on her status, and not receiving treatment if she required it. According to her the doctor did not explain to her why she did not start medication. It is possible, however, that the doctor might have explained why she has not started medication but she did not understand what the doctor told her. The communication between the doctor and this informant has not been nearly adequate. She was not sure about her HIV status and as a result she might easily identify herself as HIV negative.

The above case shows that it is important for the doctors to make sure that immigrant patients understand the information they receive. (Andrulis & Brach, 2007) argue that a failure to communicate clearly can result in unnecessary return for treatment or lead to pain or adverse events. This and other similar unpleasant issues might be prevented if a doctor uses qualified interpreters during communications with patients who are not fluent in the local language.

The majority of immigrant women living with HIV in this study are not satisfied with their communication with healthcare providers. However, some of the informants actually are satisfied with their communication with healthcare providers. Those who were satisfied said that doctors showed them a high level of concern regarding their wellbeing, gave them hope that they wouldn't die of HIV, explained to them how they should take their HIV medication and what they should expect as far as side effects are concerned. Some informants compared their communication with healthcare providers in other countries, and appreciate the care they receive in Norway. One informant, who lived in another European country before she came to Norway, said that she had a bad experience with healthcare providers the previous country. When she came to Norway she felt she was being respected and valued. She had a very good relationship with a female doctor who she met in her first consultation in Norway.

Another informant also felt she had a good relationship with a female doctor she had in the beginning of her treatment. However, as people who live in the refugee camps need to move from place to place till they get their final residence permit, it is necessary also to change doctors. Therefore, it was necessary for this informant to change from her female doctor to a male doctor, and she is not satisfied with her relationship with this new male doctor. This situation gives us a clear understanding of gender difficulties that may hinder the doctor-patient relationship. Female doctors seem to have more understanding of culture differences and seem to be more sympathetic towards people living with HIV. It could also be due to the fact that the patients are female, so is more comfortable discussing HIV with a female doctor.

5.3 Use of interpreters

The findings in this study show that language difficulties are one of the major barriers that affect communication between Immigrant women living with HIV and healthcare providers in Norway. Many immigrant patients need to use interpreters during communication with healthcare providers because of this language barrier. All healthcare services in Norway are obliged to use qualified interpreters when healthcare providers communicate with patients who do not speak common language with the healthcare worker (E. Kale & Syed, 2010).

This study found that immigrant women with HIV are aware of the importance of using interpreters for their communication with healthcare providers. Most of the women in this study said that their inability to understand and speak Norwegian and English creates misunderstanding and limits them from getting information they need. The women are constrained from asking questions, even if they wish to do so. As one informant said, they just keep quiet unless an interpreter is present during the visit. Both immigrant women with HIV informants and informant interpreters in this study agree that it is crucial to use interpreters to secure quality communication. Immigrant patients prefer interpreters who empathize with them (Svela, 2007). The informants in this study also reported that having interpreters who empathize with them is important. They said it would have been preferable to use interpreters who are HIV positive, so that they have a better understanding of their unique challenges.

Most of the communications with healthcare providers happens without the use of interpreters. Other studies in Norway also confirm that healthcare providers do not usually use interpreters when they communicate with immigrant patients (Kale and Syed 2010). The communication with interpreters depends on the interpreter's ability to abide by the professional code of conduct required of interpreters and in turn the trust the interpreter receives from the immigrant patient (Svela, 2007).

5.3.1 Stigma and the role of interpreters

Disclosing personal information is associated with stigma, and in turn stigma is linked to the concept of shame and disgrace (Goffman, 1963). Stigma comes from the belief that being HIV positive means death, and this study found that informants who are diagnosed as HIV positive feel close to death.

Stigma associated with HIV/AIDS has multidimensional effects on women's health and well-being. The stigma associated with HIV is understood to be a second epidemic because of the severe impact it has on the people who are HIV positive (Carr & Gramling, 2004). Immigrants living with

HIV become overwhelmed by the stigma they experience after their diagnoses with HIV, and they do not perceive themselves in the same way as they did in the past. As a result of having wrong perceptions about HIV, many HIV positive people feel that they are not equal to the rest of the society because of their HIV status, and they also feel others feel the same way about them (Kleven, 2006).

A study by Karago-Odongo (2008) show that some immigrants with HIV travel long distance to access both health services and interpreters, so that they will not be recognized by people whom they already know in their own communities. Due to stigma, informants in this study are more concerned about the psychosocial impact of HIV than the actual physiological and health impact on them. Some of the informants avoided taking their medication due to fear of being caught and then stigmatized. A good example of this is one informant who avoided taking her HIV medication for three days while her friends were visiting her. Other studies have also shown that HIV positive immigrants struggle to hide their HIV status from others. Many African immigrants fear disclosing their HIV positive status to family, friends, sexual partners and interpreters. Many believe that HIV is transmitted due to a curse, due to misbehaving, or due to engaging in prostitution (Karago-Odongo, 2008).

One of the informants in this study was shocked when she was diagnosed with HIV. Her first reaction was, “why me, I am not a prostitute and I have never behaved improperly.” Such beliefs contribute to patient’s self-isolation from people of their own community. Many of the informants in this study felt dishonest for not disclosing their HIV status to friends and family. Although they acknowledged the benefit of sharing their pain with their close people, they feel that they would not be able to handle the reaction and rejection from their family and friends that might occur when they disclose their HIV status.

Informants are not only hiding their HIV status from friends and family, they usually hide their HIV status from interpreters that are from their own countries. This means they usually don’t communicate well with their healthcare providers when interpreters are involved. Therefore using interpreters to communicate with their healthcare providers can be challenging for many of the HIV positive people.

5.3.2 Reluctance to use interpreters

Immigrant women in this study expressed their deep suspicion towards interpreters that are also of African background. They fear that interpreters with African backgrounds may expose

their HIV status to other Africans in their community. The African immigrant population in Norway is not large; so many Africans meet each other in different social occasions. Interpreters in many cases meet HIV positive African immigrants at different occasions. These types of social occasions may lead to gossip releasing of information about their HIV positive status. Immigrant women are afraid that this would destroy their social life and standing in their community. They are also afraid that the information will eventually get back their relatives in their home countries. It should be noted that at least some of this fear of exposure is self-imposed.

Informant interpreters and an immigrant employee at Aksept said that some African immigrant groups are especially sensitive to such leakage of HIV status. Immigrant women with HIV who are sensitive therefore choose to avoid using interpreters when they communicate with healthcare providers. Despite the risk of not understanding the information they get from healthcare providers, they choose not to use interpreters at all. It is important to mention that three of the interviews with Immigrant women living with HIV in this study were conducted through one specific employee at Aksept. This was due to the fact that the informants expressed clearly that they did not wish to be interviewed with an external interpreter present. They chose this one interpreter because they knew her and trusted her. She has shown that she does not expose HIV status of clients to other immigrants. It is however difficult to expect a similar level of trust with other interpreters since they do not interact often with these patients.

Another concern for Immigrant women living with HIV is using several different interpreters in their visits with their doctors. They are afraid that using various interpreters forces them to disclose their HIV status to many people who are part of their immigrant community. Informants are not confident on the confidentiality of these interpreters. There is a high level of suspicion and mistrust towards interpreters by immigrant HIV positive women. All the informants who use interpreters suggested the use of one permanent interpreter when they communicate with healthcare providers. Informants said that with one interpreter they would have better relationship and they would not be afraid to reveal their health issue to that interpreter. But when they are required to use various interpreters, they prefer to hide their health issues and concerns. However, due to limited resources, it is unrealistic to expect that healthcare services allocate one permanent interpreter to each HIV positive immigrant. Many healthcare institutions do not hire interpreters as part of their work force, but choose to hire

interpreters from external translator agencies on a cost for time basis. Most interpreters work on a part-time basis and are called by translator agencies on a daily basis. Therefore, interpreters are not always available as needed (Svela, 2007). This situation affects availability of qualified interpreters.

It is clear that qualified interpreters are important to allow successful communication between immigrant women with HIV and healthcare providers. Healthcare services need to make available qualified interpreters who respect confidentiality, have high integrity, and respect the concerns and wishes of Immigrant women living with HIV.

5.4 Limitation of the study

This study was subject to a number of limitations. During the data collection it was planned to recruit informants through Ullevål University Hospital which may have given us a more representative picture, but getting sample from there has been difficult. And recruiting of informants was done only through Aksept. Lack of data from healthcare providers and not being able to recruit Non-African immigrant women living with HIV are also limitations for this study.

Finally, being an African immigrant I might have had both positive and negative effect on data collection. For many potential informants it was unacceptable that I was an African and wanted to interview them.

5.5. Conclusion

The findings in this study are in line with other international studies on HIV positive immigrants, and show clearly that the health information HIV positive people are getting is quite limited, due to language barriers, culture differences, difficulties in trusting interpreters, and the fear of stigmatization. All of these factors were found to be hindrance to good communication between healthcare providers and Immigrant women living with HIV.

Information is very important for HIV patients; it is a source of hope and future. Many of the informants said that the sources of information they are mainly using are either sharing their experiences with people who have the same problem or information obtained from the internet. Getting information from healthcare providers is reported to be limited. As a result, some of the informants still do not have a clear understanding of their HIV status. Hence having good communication with immigrant patients is very crucial; however, this study found that communication between doctors and patients is best described as one way

communication, from the doctor to the patient only. This could be because it is the doctor who has the information or it could be because it is helpful to the patient to listen. But the quality of the doctor-patient relationship is important to both parties.

The better the relationship is in terms of mutual respect, knowledge, trust, shared values and perspectives about disease and life, and time spent together, the better will be the amount and quality of information about the patient's disease that is transferred in both directions, enhancing the accuracy of diagnoses and increasing the patient's knowledge about their disease and health. However, when this relationship is poor the physician's ability to make a full assessment is compromised and the patient is more likely to distrust the diagnosis and the proposed treatment, causing decreased compliance to the medical advice. The physician may be viewed as superior to the patient, because the physician has the knowledge and credentials, and is most often the one that is on home ground. A patient must have confidence in the competence of their doctor and must feel that they can confide in him or her. In most cases, the establishment of good rapport with a patient is important, and it is more so in the case of HIV/AIDS patients and their healthcare providers.

This study shows clearly that immigrant women need interpreters when they communicate with healthcare providers. However, most informants in this study avoid using interpreters so that they do not risk compromising the privacy of their HIV positive status and expose themselves to stigma. Women choose to use their broken language to communicate with healthcare providers rather than using interpreters from their same community. Women also expressed their frustration over being exposed to different interpreters. As a result of using different interpreters women lack the possibility of building trust with their interpreters, and this leads them to mistrust and avoid interpreters.

Interpreters in this study claimed that without them the communication between doctors and immigrant patients is very limited. Immigrant women living with HIV also agree with the need to have interpreters during their communication with healthcare providers. However, they still prefer to use their broken language to communicate with their healthcare providers, instead of exposing that they are HIV positive to people from their community, including interpreters from their own country of origin.

5.5.1 Recommendations

This area calls for further research which also involves immigrant women who are from non-African countries. This study has just touched the tip of the “ice-berg” in the area of communication between doctors and immigrant women living with HIV. To see if this problem exists among the wider immigrant society it will be good to have a study that includes Non-African immigrant women. Improving access on health information and communication requires knowing both sides of the problem. For that we need a qualitative study on how healthcare providers perceive their communication with immigrant women living with HIV.

There is a need to clarify ways in which to strengthen communication and information access to immigrant women living with HIV. Healthcare providers need to be aware and recognize the language and cultural barriers of immigrant women living with HIV. It is equally important that their need for confidentiality be taken seriously. Also, immigrant women living with HIV need to be informed and guaranteed that the healthcare services respect their need for privacy. Immigrant women living with HIV should be able to make an informed choice, about the use of interpreters. Informed choice entails that they should be informed about the possible consequences of using and also of not using interpreters. It is very clear that it is a risk for immigrant patients to communicate with healthcare providers without interpreters. Immigrant patients need to be assured that interpreters are guided by a professional code of conduct that includes patient confidentiality. Healthcare services need to make sure that they only use qualified interpreters that respect the professional code of conduct for interpreters.

This study further recommends the following principles be adhered in order to establish the best possible communication and between immigrant women living with HIV and healthcare providers.

- To communicate effectively healthcare providers need to listen to patients, ask for and respect their views about their health, and respond to their concerns and preferences.
- Immigrant women living with HIV can be shy, and need to be encouraged by healthcare providers to converse with them.
- Information need to be provided to patients well in advance of their first visit to minimize misunderstanding and wrong expectations.
- One permanent doctor and one qualified interpreter need to be assigned, if it is possible.

- Information materials need to be prepared in different languages and made available at blood test centers, doctor's offices, and in other venues where immigrants meet.

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7. APPENDIXES

ANNEX 1: Interview guide for HIV positive immigrant women

Background

1. Age
2. Marital status
3. When did you come to Norway?
4. When did you learn about your HIV status for the first time?
5. What happened when you got to know that you have HIV?
6. Tell me your experiences as HIV positive person.
7. Is there anyone who you have told your HIV status to? If yes who?
8. And why that or those people in particular?
9. If no what is your reason why you are not telling people who you know?

Communication

1. Tell me how it was for you when you met your doctor for the first time here in Norway?
2. What language you use to talk to doctors and nurses?
3. How do you think the way your communication is with your doctor and nurses?
4. How much of the conversation you feel you understand from your doctor?
5. Do you ask question when you don't understand what your doctor is explaining?
6. Does your doctor ask you if you have understood everything he said to you before leaving the office?
7. Do you have a female or a male doctor?

8. Who do you prefer to talk to a female or male doctor?
9. Why?
10. Tell me who as healthcare workers you prefer to talk to nurse or doctor?
11. Why?
12. Do you feel you have enough time with your doctor during the consultation?

Interpreters

1. Do you use interpreters when you are talking to healthcare workers?
2. If yes how is it for you to use interpreters?
3. If no tell me your reason why you do not use interpreter?
4. What is the good thing about interpreter?
5. Do you prefer to talk to a man interpreter or a woman?
6. Why?
7. What do you think should be done to make it better?

Information

1. Do you get information on your health?
2. Who gives you information?
3. How much information do you get from your doctor?
4. What health information sources are you familiar with? Books, booklets internet, TV, brochure, nurses' doctors?
5. Do you get information on your language?
6. If not how much of the information do you understand?
7. What do you think can be done to make the information available?

ANNEX 2: Interview guide for interpreters

1. Tell me your experience as an interpreter
2. How do interpreters contribute to the exchange of information between healthcare workers and immigrants with HIV/AIDS?
3. What kind of expectations do healthcare workers and patients have from interpreters?
4. How do you see your role as interpreter for patients with HIV?
5. How do you see confidentiality when it comes to HIV PATIENTS?
6. What is the best thing about your work as an interpreter?
7. What are the challenges of your work as an interpreter?
8. Have you ever experienced rejection as an interpreter?
9. If yes, what was the reason(s)?
10. Tell me what you think about the way immigrant women communicate with healthcare workers?
11. Do you think immigrant women with HIV get adequate information about the disease and treatment options from healthcare workers?

ANNEX 3: Request for participation

Introduction

My name is Wolela Haile. I'm doing a master in international health in Norway and this research is part of my study. I'm conducting interviews to explore the communication between immigrant women with HIV/AIDS and healthcare workers in Norway. And eventually investigate immigrant women's perception and needs for good communication with healthcare workers.

I would like to have a discussion with you about your experiences talking to Norwegian health workers. We may need to meet again to clarify issues that might arise from our discussion. Your identity will be treated with confidentiality and the information that you provide will be used exclusively for the purpose of the study.

Your name will not be written on the interview note or anywhere else and will never be used in connection with any of the information you tell. You don't have to discuss issues that you do not want to and you may end the interview any time. If you want to withdraw from the study any time along the study process you will not be obliged to continue or give reasons for doing so.

Refusing to participate or withdrawing from the study along the process will not have any consequences on you. However, the information that you provide during the discussions will help to improve the communication between immigrant women with HIV and health workers in Norway.

The findings of the interviews might get published and contribute to understanding of barriers for good communication between health workers and immigrant women with HIV Norway.

I would greatly appreciate your help in responding to the interview. If you have any questions or anything that is not clear please feel free to ask me when we meet for the interviews.

If you are clear with the information provided and agree to participate, please inform the health professional and we shall meet at the time of your convenience for the interview.

ANNEX 4: Consent Form

The undersigned has been informed that the purpose of this research is to explore the communication between immigrant women with HIV/AIDS and healthcare workers in Norway. And eventually investigate immigrant women's perception and needs for good communication with healthcare workers.

I have been informed that I am going to have discussions with the researcher about communication with Norwegian health workers and the discussion might be repeated, if there is a need to clarify issues that might arise from the discussion.

I have also been informed that the information that I give will exclusively be used for this study and the findings possibly will get published, but that my identity will be treated with confidentiality and my name will not be used in connection with the information that I gave.

I have also been informed that I can refuse to discuss issues that I don't want to discuss and can stop the interview any time I want, and that I will not be obliged to continue to participate in the study or give reasons for doing so.

I have also been informed that I can stop participating any time along the study process and that refusing to participate or withdrawing from the study will not have any consequences on me.

I agree to participate in this research.

Signature

Date

Signature -----

Date -----